“I still, I still, I still, I still…”
The Voice of the Older Person with advanced dementia in residential aged care: an ethnography exploring what it means for the Person to have their Voice

By

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“Families’ positive interaction with their relative means appreciating the person’s voice as relationally meaningful, rather than necessarily comprehending its content” (p.197).

‘’In this context, it would appear that any resistance or substitution of alternative paradigms in the social imaginary of old age may depend less on clinical research and technical breakthroughs and more on our imagination, specifically our creative ability to awaken other, equally powerful, metaphors which might resonate with us’’ (Pickard 2014, p. 560).

DEDICATION

To my mother, Muriel Leggett, who gave me opportunities to share life with elders and be part of an Aged Care Home. And when it came her time, voiced her courage as she resided in an Aged Care Home.

To my father, Len Leggett, who inspired and supported me in my study. And when it came his time, voiced his enjoyment as he resided in an Aged Care Home.

To all the elders who have participated in my life, implanting wisdom, resilience, faith and hope.

To all the elders who became central participants of this thesis for their friendships and voices.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university;
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

Signature

Julie Elizabeth Simpson

22nd February, 2024

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GLOSSARY OF ABBREVIATIONS

ABC	Australian Broadcasting Commission (television and radio)
ACFI	Aged Care Funding Instrument (prior to 2021)
ACSPRI	Australian Consortium for Social and Political Research Inc.
AIHW	Australian Institute Health and Welfare: National Aged Care Data Clearinghouse
CASP	Critical Appraisal Skills Programme (United Kingdom)
DCM	Dementia Care Mapping
HREC	Human Research and Ethics Committee, Flinders University, South Australia
NDSP	National Dementia Support Program (Australian)
NATSEM	National Centre for Social and Economic Modelling (Australian)
NHMRC	National Health and Medical Research Council (Australian)
NHS	National Health Service (British)
WHO	World Health Organization

DEFINITIONS OF STAFF TERMS AND ROLES (USED IN AUSTRALIA)

ACFI: used before 2021 to appraise permanent residents' care needs and the annual subsidy available through the Australian Government to make aged care affordable and accessible. There were 3 Domains of assessment of each resident: activities of daily living, cognition and behaviour and complex health care.

Activities of Daily Living (ADLs): an essential set of personal care activities, including bathing, washing, dressing, assisting in eating and drinking, getting in and out of bed, getting to and from the toilet and continence management.

Aged Care Standards: the legislated mandated standards for aged care by the Department of Health and Aged Care, and monitored by regular inspections of the personnel of Aged Care Quality and Safety Commission

Capability Coordinator/ Lifestyle coordinator: a staff member qualified to lead the capability/ lifestyle team in planning and providing social and interactive activities individually and in groups that encourage the well-being, interests, and abilities of residents.

Capability Assistant/ Lifestyle Assistant: a staff member with certificate level training who provides capability/lifestyle activities as defined above.

Care Coordinator: a staff member who is a registered nurse often with a minimum of five years post-graduate experience including experience in and approved post registration qualifications who oversees the clinical care team of nurses, carers and allied health workers.

Carer: a staff member with certificate level training who provides direct care to residents, assisting them with their ADLs and various activities during the day and night.

Chaplain: a staff member with particular qualifications often in theology and/or pastoral care providing one to one pastoral care to residents, their families and staff and group activities such as religious worship services and spiritual reminiscence

Cleaner: a staff member who ensures the cleanliness of residents' private rooms, ensuites and communal and service delivery areas.

Comfort (Princess) Chair: is large with in-built cushioning covering its sturdy frame. It is used by a person who is no longer able to move around independently and needs a high level of comfortable support for the different parts of their body. A person is placed and moved around the aged care home in this chair by staff and usually spends several hours in it each day.

Enrolled Nurse: a staff member who has completed enrolled nurse training and provides nursing care according to her qualifications under the direction and supervision of a registered nurse.

Hairdresser: a qualified and usually sub-contracted by the organisation/aged care home to provide hairdressing and personal grooming services to the residents.

House Keeping Manager: a staff member qualified to plan for and lead the catering, cleaning and organising of private rooms in the aged care home.

Laundry Person: a staff member who ensures the labelling and laundering of residents' clothing items and some items used in the aged care home.

Memory Support Houses: designates the houses/areas where people with advanced dementia reside in the aged care home, and which cater for their specific care and social needs.

Multi-disciplinary Team: a range of qualified people in specific disciplines who usually meet regularly and work together to plan and provide the holistic care of each resident.

Registered Nurse: a member of staff and a nurse who has completed a minimum of 3 years' training and is registered with the nursing and midwifery, is responsible for overseeing and providing nursing care and delegates care to enrolled nurses and other healthcare workers.

Residential Services Manager: a qualified manager or registered nurse who oversees the management of the local aged care home.

Social-Spiritual Care Plan: a summary compiled by lifestyle/capability and chaplain, if on staff, at the early stage of a person's residing in the aged care home, uploaded to the resident's care record, and regularly reviewed. The collected input from the resident and/or their family member/ friend about the resident's history, relationships, needs, preferences and choices of how they have enjoyed and/or wish to spend their day to guide care and support provided. This care plan is updated if there are any changes.

Substitute Decision Maker: usually a family member legally designated by the person, while they have cognitive capacity, to oversee their care, legal and financial arrangements and decisions, and provide informed consent for the person as required.

Volunteer: often considered an unpaid member of staff who provides their care one to one and in groups under the supervision of paid staff to the same standards as regular members of staff.

GLOSSARY OF ABBREVIATIONS CH 5 (METHODS) & CHS 6 TO 8 (DATA ANALYSIS)

Participants:

Central Participants:	Pseudonym first name
Family Members:	Relationship with the person and pseudonym
Staff Members:	Role and pseudonym
Researcher:	Julie

Data Form:

AT	Audio Transcript
FI	Family Member Interview
GA	Group Activity
GI	Group Interaction
RFI	Resident-Family Member Interview
RI	Resident 1:1 Interaction
SI	Staff Member Interview (No. 1, 2 and 3)
PhI	Phone Interview

Data Source:

Home 1	Book 1
Home 2	Book 2
OG	Observational Grid
PN	Pseudonym Notes
POD	Participant Observation Diary (Book 1 or Book 2)
RCP	Resident Social-Spiritual Care Plan
RJ	Reflexive Journal (Book 1 or Book 2)
RPA	Resident's Personal Artefacts

Location in Home:

ARm	Activity Room
Café	Cafe
Ch	Chapel
CCY	Café-Courtyard
DRm	Dining Room
LRm	Lounge Room
ORm	Own Room

PRESENTATIONS

July, 2016- ACSPRI Social Science Methodology Conference, University of Technology, Sydney, New South Wales, Australia, Simpson, J. Response Abstract to Conference Publication by Hodgins, M, Dadich, A & Collier, A. Paper titled: Negotiating access and undertaking video reflexive ethnography in community-based palliative care.

6th May, 2018- Pre-conference Seminar on Research, Spiritual Care Australia Conference, Newcastle, New South Wales, Australia, Simpson, J. Paper titled: Research and Praxis: The deep connection!

5th November, 2018- College of Nursing and Health Sciences Inaugural Higher Degree Research Students Conference, Simpson, J. Paper titled: The Voice of the Older Person with advanced dementia in residential aged care: What does it mean for a resident to have their voice?

28th November, 2018- Volunteers' Training Day, St Pauls Lutheran Homes, Hahndorf, South Australia, Simpson, J. Paper titled: Communicating with the Person with advanced dementia.

27th – 30th October, 2019- 8th International Conference on Ageing and Spirituality, Canberra, Australia, Old Parliament House, Canberra, Australia, Simpson, J. Paper titled: The voice of the Person with advanced dementia and the support of spiritual care.

18th September, 2020- Anglican Pastoral Care Seminar, St Augustine's Anglican Church Hall, Victor Harbor, South Australia, Simpson, J. Paper titled: Being in relationship with People with dementia.

6th December, 2022- Lifecare Chaplains' Network Meeting, Churches of Christ Lifecare, Reynella, South Australia, Simpson, J. Paper titled: The Many Layers of Pastoral Care Conversations.

ABSTRACT

The voice of the person with advanced dementia is a significant aspect of how each person lives their daily life in residential aged care. This doctoral thesis explores how the person continues to express and /or enact their voice in this stage of their life. These features become the person's pathway to expressing their continuing presence and participation in the world.

The survey of the various contexts in which people with advanced dementia live discerned that they are often stigmatised, stereotyped, and described as deficit and unable to communicate. An integrative literature review found a dearth of research literature exploring how the person with advanced dementia expresses or enacts their voice from their perspective and lived experience. This thesis contrasts with previous studies in positioning people with advanced dementia as central participants and contributors, and with respect to their continuing capabilities and capacities to communicate. My original contribution to knowledge is the development of an understanding of the voice of the person with advanced dementia, how and why the person with advanced dementia expresses and enacts their voice in their lived experience, and the significance this has for them.

A theology and ethics of developing relationships of respect, recognition and reciprocity with people with advanced dementia underpins this thesis. A qualitative methodology of ethnography has embraced strength-based principles and an appreciative inquiry approach. The research was undertaken in two aged care homes in the same South Australian organisation, with twelve people becoming central participants. This study utilised various methods, including conversations, interactions and participant observation to facilitate their voices and contribution. Family and staff members in diverse roles were interviewed about how they promote the person's voice. The research findings evidence that the person continues to have their voice, and clarify the significance this has for them. A range of themes focus on their voice being an aspect of their social, emotional and spiritual dimension. These themes include: the significance of relationships to the person; the person's voice repertoire; the person's voice in interactions and activities; the person's voice in their continuing agency, identity and storied-life; the person's voice in reciprocity and contribution; the person's voice expressing their emotionality; the person's voice making important connections; and the person's sense of meaning and spiritual significance in engaging with another alongside them.

Acknowledgement of and attentiveness to the person's voice is the crucial segue into providing appropriate, accurate, holistic, and excellent care. Integrating this approach in care enables the person to continue to live a fulfilling and flourishing life. The findings of this thesis contribute to the ongoing development of care policy and praxis that recognises, strengthens and promotes the voice of the person with advanced dementia living in residential aged care and in wider society.

PROLOGUE

A Saturday morning. We met as a family around Dad's bed after he had been admitted to this major public hospital seven days before. An ambulance had transferred him from the aged care home where he lived to the local country hospital. Diagnosed with pneumonia, he had been transferred by ambulance to the major acute hospital about an hour away. A few days later Dad's physician told us the medical team were deciding whether to continue his antibiotic medication as this was not improving his condition. Sensing we were into the palliative phase, and as his substitute decision maker I directed that my father's antibiotic be discontinued. According to Dad's Advanced Care Directives he wanted to be as pain free and comfortable as possible without life-prolonging interventions.

Over that week I stayed with Dad for many hours each day as he groaned with pain, discomfort and delirium. My frequent attempts to get the doctors and nurses to hear, observe and respond with appropriate medications went unheeded. My requests for referral to the palliative care team were overlooked. With little respite Dad and I were still able to have valuable but brief interactions. Noticing him becoming weaker I had the growing sense that family needed to gather. Saturday morning in the medical ward was quiet, with no specialists, few allied health workers and only the occasional intern and nurses doing ward rounds. So this was a good uninterrupted time for our family to gather around Dad/Grandpa/Pa.

Saturday morning was mercifully Dad's one period of longer reprieve in the week. On this autumn morning the sun poured into his room. Dad was sitting up in bed looking weak and small, but ready and looking forward to our arrival. Our family had always been an important part of Dad's life. Dad/Grandpa/Pa smiled as each one of us came up close to greet him. We soon realised Dad was aware of the significance of this moment. Holding each of us by the hand he expressed a few words and gestures of love as his forever gift to each of us to remember him by. After our gathering Dad again went into delirium, with his remonstrations continuing to be ignored by the medical team. Nevertheless, as I lay on a stretcher beside Dad on his last night and heard his last calm breaths, I was grateful for this last precious time we had been together.

This entire experience was such a marked contrast to Dad’s life in the residential aged care home where he had resided happily for seven years. After Mum’s death he had lived alone in his own home. He felt lonely, despite the regular visits of family and the daily support of a carer. Then, having had respite in the aged care home he announced he was staying, having vowed he would “never go into such a place”. The home transformed his life from loneliness. He participated in very good holistic care and relationships with staff, and with his mates around the dining table, sitting in the courtyard together, attending church services and other activities. We witnessed the mask of advanced dementia dropping away. As family we were all glad that Dad’s final years had become so meaningful and enjoyable. He had retained his voice and dignified demeanour. Dad’s personhood was recognised, his personal characteristics respected, and his capabilities and capacities encouraged.

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CHAPTER 1 INTRODUCTION

Impetus for this Thesis

My interest in and impetus to undertake this study is founded in my personal and professional experiences of people with advanced dementia. The Prologue depicts the unique experience of journeying with my father during his latter years, particularly in his difficult palliative care, and what enhanced and what hindered his expression of his voice in this last phase of his life. I have also had four decades of professional experiences of interacting with and pastorally caring for people with advanced dementia in the community, aged care homes and hospitals. Yet nothing prepared me for the experience of being alongside each of my parents, who each lived with advanced dementia, firstly my mother and nearly two decades later my father, in different care settings. They endured practices that were far from dignified and respectful, even negligent, and I witnessed their voices being disregarded and ignored. While I and my family understood that each of them was able to express their needs, choices, opinions and concerns until the last days of their lives, their perspectives were overlooked and I needed to be constantly present to advocate on their behalf. In addition, my professional experiences as both a hospital and aged care chaplain have given me an appreciation of the continuing capabilities and capacities of people with advanced dementia in being able to voice their needs, choices, opinions and concerns, and their continuing identity and storied-life. These various pathways were my incentive to explore and promote the lived experience and voice of the person with advanced dementia.

1.1 The Contested Notion of the Person's Voice

In this thesis I am specifically focusing on people with *advanced* dementia. The notion of the voice of the person with advanced dementia has been and continues to be a contested issue. This may be due in major part to the ongoing prevalence of the stereotyping and stigmatisation of people with advanced dementia and their carers within society (Alzheimer's Disease International 2019, pp. 13-6). The media, for example in television news items, plays a significant role in propagating stereotypical images of people with advanced dementia. Often these images are of vague embodied forms "slumped in chairs, disengaged, not doing anything, or minimally interacting" (Gove et al. 2017, p. 954ff). Such images suggest the person with advanced dementia lacks the capability and capacity to take initiative to communicate and be responsive and reciprocal in interacting with others. Young, Orange and Lind (2019) define stigma as occurring:

> *when persons with relative social, economic, or political power internalise generalised negative beliefs (stereotypes) which then manifest as negative emotional responses (prejudice) and negative behavioural responses (discrimination) (p. 17).*

Stigma has significant power to have a cyclical or domino effect in influencing the attitudes and perspectives of people within the wider community. A study by Gove et al. (2017) focused on the perceptions of General Practitioners regarding the attitudes and responses of people in society towards people with dementia. This research found that stereotypical images of people with advanced dementia are prevalent in the wider community, affecting attitudes towards people living with early-stage dementia and their families. These images may affect the ways that people with dementia generally are perceived by others with prejudice and discrimination. Bryden (2006), with a lived experience of dementia, concurs with the study of Gove et al. (2017) in stating:

> *…the stereotype of someone in the later stages of the diseases that cause dementia give rise to the stigma that isolates us. You say we do not remember, so we cannot understand. We do not know so it is OK to distance yourself from us. And you treat us with fear and dread…we cannot contribute to society…my opinion is no longer sought, and I am thought to lack insight, so it does not matter that I am excluded (Bryden 2006, p. 40).*

Bryden (2006) argues that presumptions about people with advanced dementia set up the patterns of the stigmatising and abjection of people with earlier stage dementia. There appears to be a common view that people with advanced dementia do not have a voice, let alone the capability and capacity to express their voice. So they are overlooked and excluded. This perception and response is lamentable. Yet ignorance and ostracism still pervade many perceptions and experiences of the person with dementia from receiving the diagnosis onwards (Swaffer 2016). Anecdotally, in conversation with others during my doctoral candidature some have responded to my research topic with comments such as, “That will be a very quiet thesis.”

The advanced stage of dementia is often portrayed as a form of ‘living death’ (Brannelly 2011) in which people are no longer seen as having personhood, or even able to engage with others and their environment. For the person’s family and informal caregivers this stage is often construed as a ‘living bereavement’ (Downs 2011, p. 248). These perceptions persist, intertwined with those of many family, formal care givers, and people in the wider community that the person is “no longer the same” (Hennelly & O'Shea 2022, p. 2111). Therefore, the assumption is that the person’s capabilities and capacities, along with their personhood are lost. These perceptions of the person with advanced dementia indicate that for the person and those closely associated with them, this experience is permeated with strong emotions of grief, loss, fear and uncertainty (Walmsley & McCormack 2017). These emotions are borne of the perplexing changes and challenges that people experience and must navigate.

Prejudicial attitudes may also be held by health care professionals and workers (Gove et al. 2017). Anecdotally, on several occasions I have been present in an aged care home or hospital alongside a person as they expressed or enacted their voice. I have noted responses of health professionals ranging from surprise and patronising the person, to their being ignored or spoken over as a family member speaks for them, or the health professional ignores their contribution, denying them the opportunity to respond or contribute to their situation. Such responses indicate a lack of respect, dignity, recognition and understanding of the person, and a total disregard for their ongoing capacities and capabilities. This thesis responds to these misconceptions and prejudices about people living with advanced dementia within residential aged care[1].

In this thesis I propose that much can be learnt from the older person with advanced dementia about what promotes their voice in residential aged care. In this thesis I use the term 'the voice of the person'[2] as a broad, descriptive research goal to mean the ways the person expresses or enacts their inner and outer lived experiences in their situation. Therefore, this thesis focuses on how and why the person expresses or enacts their voice in their lived experience of self, with others, and in participating in their context, and what enables the person's voice.

1.2 Focusing on the Person with Advanced Dementia

Before moving to specific understandings of the person, this section provides some preliminary general information of the Australian context regarding people with advanced dementia. The following Australian statistics are collated and updated by the Australian Institute of Health and Welfare on its web-site (AIHW 2022).

Prevalence of People with dementia in Australia

The exact number of people living with dementia is not known. In 2022, it was estimated that there were 401,300 (AIHW estimate) Australians living with dementia. Based on AIHW estimates, this is equivalent to 15 people with dementia per 1,000 Australians, which increases to 84 people with dementia per 1,000 Australians aged 65 and over.

With an ageing and growing population, it is predicted that the number of Australians with dementia will more than double by 2058 to 849,300 (533,800 women and 315,500 men).

(https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary#Common)

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[1] I have chosen to use the term 'residential aged care' to apply generally to the setting in the aged care sector and apply the specific term 'aged care home', to the two *specific places* where the research took place, namely Home One and Home Two. 'Aged care home' is the term used in the organisation where I am a chaplain. The terms, 'residential care facility', or 'nursing home' are commonly applied in Australia. In my Masters research I found that when this place of residence is fashioned as a home, named a home, and defines care as relationships, *the* person liv*ing* there is more likely to call the place "home" (Simpson 2006).

[2] The term 'the person' or 'people' refers in this thesis to the person, or people with advanced dementia. I have applied these terms to people who became the central participants in the field research. By using this terminology I wish to emphasise the person's status and positioning in this study. I use 'the person' or 'people' throughout to avoid confusion.

Given increasing life expectancy and the rise in the number of people living with dementia, significant numbers of people, their families and communities living with dementia will continue into the experience of advanced dementia.

Prevalence of People with dementia in Residential Aged Care

Currently in Australia most people living with advanced dementia no longer live independently in the community, and dwell in residential aged care. The exact number of people living with advanced dementia is not known. What is known is that among people with dementia in Australia, 1 in 3 people live in cared accommodation. In 2019–20, there were over 244,000 people living in permanent residential aged care, and more than half (54% or about 132,000) of these people had dementia. 80% of people with dementia had an ACFI (see Glossary) high care need rating in every care domain, indicating they were living with moderate to advanced dementia.

(https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary#Impact)

Currently in Australia there are significant numbers of people with advanced dementia with high care needs, living in full-time residential care for ongoing assistance and support with their every-day lives. People in the advanced stage of dementia may live months and even several years in an aged care home (Brown & Tolson 2020).

A recent definition of advanced dementia has been formulated by Alzheimer Scotland in partnership with an expert commission:

> *Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics (Alzheimer Scotland 2019, pp. 14-5)*.

This definition seems comprehensive in outlining the various issues and domains of care pertinent to the advanced stage of the disease, recognising each person's experience as "unique". However, in its clinical focus this definition seems devoid of the person, their characteristics of personhood, and recognition of the person's lived experience in this significant final phase of their life. As the disease progresses, the person's quality of life is paramount. This thesis argues that care of the person with advanced dementia demands holistic knowledge of the person within trusting respectful relationships. Such care provision is centred on the person and is attentive to their voice with respect to their desires, needs, choices, concerns and lifestyle (Brown & Tolson 2020). Therefore, it is the responsibility of those providing care and services to understand the lived experience of people with advanced dementia. This study seeks to recognise and understand the voices of people with advanced dementia through developing relationships with them and engaging with them in interactions and activities.

Yet how it is possible for a person with advanced dementia to continue to experience life that is fulfilling and flourishing may also be contested, as this has been found to be deficit in many residential care settings.

1.3 The Challenges and Deficits in Australian Residential Aged Care

In the Australian aged care sector there exists decades of neglect. Decisions made by successive federal governments have diminished the priority and funding of aged care, with "resultant failures and shortfalls" (Royal Commission into Aged Care Quality and Safety 2021b). The Australian Royal Commission into Aged Care Quality and Safety was instigated with a substantial critical agenda as its Terms of Reference (Royal Commission into Aged Care Quality and Safety 2021c, pp. 192-7). The Final Report of the Australian Royal Commission catalogued and condemned the prevalence of sub-standard practices, including negligence and abuse, in many aged care services (Royal Commission into Aged Care Quality and Safety 2021a, pp. 24-5, 35; 2021b, p. 9; 2021c, p. 68). The Final Report also revealed the inequity in accessing high quality aged care throughout the aged care sector, across the cities and particularly regionally, rurally and remotely (Royal Commission into Aged Care Quality and Safety 2021c, p. 111f). To address the malaise within the aged care sector the Royal Commission has advocated for a total "rebuild" with major reformation in the fundamentals. This requires the redrafting of the Aged Care Act to legislate standards for the aged care services sector within a rights based framework for all aged care consumers (Duckett 2020; Royal Commission into Aged Care Quality and Safety 2021b).

The Final Report has specified several alarming issues pertinent to this thesis, including under-staffing in more than half of all residential aged care settings (Eagar et al. 2019, p. 35) and the prevalence of ageism. Chair Pagone remonstrates that low staffing ratios negatively impact each person living in residential aged care. "Understaffing" means that staff do not have the time to relate meaningfully with each person, leading to care being task-oriented rather than premised on relationship, interaction with and knowing each person, and understanding their unique needs (Royal Commission into Aged Care Quality and Safety 2021b, pp. 8-9). Such limited care fails to provide for the psycho-social-spiritual needs of the person.

The Royal Commission's final report was handed down early in 2021, the second year of the Covid-19 pandemic. The effects of the pandemic in an already deficient and strained aged care system, have compounded the malaise of issues and the difficulties of implementing the recommendations for reform handed down by the Royal Commission (Cousins 2020). During the pandemic periods of social distancing, confinement of residents to their rooms and lack of social interaction, particularly with family, and in activities, exacerbated people's loneliness and social isolation (Curelaru et al. 2021). Social isolation is defined as physical separation from or minimal contact with others, and loneliness as the emotional experience of distress in response to being socially or emotionally isolated (Victor & Sullivan 2015). Less social interaction with family and neighbours in communal living causes greater risk of social isolation and loneliness (Australian Psychological Society 2018). In the absence of Australian statistics, a United Kingdom study assesses loneliness and social isolation are 22-42% more prevalent in residential aged care populations, compared with 10% prevalence in the wider community (Victor 2012). Those who experience social isolation and loneliness are at greater risk of negative health outcomes and poorer quality of life (Curelaru et al. 2021). Loneliness and social isolation deleteriously impact people in the general population, and the vulnerability of the person with dementia makes them all the more susceptible. Therefore the issues of understaffing, loneliness, and social isolation diminish the person's voice, quality of life and well-being, and may lead to their dementia progressing, and premature death (Curelaru et al. 2021). These issues must receive careful attention to safeguard the psycho-social and spiritual needs of people living in residential aged care. This thesis focuses on the importance of the person with advanced dementia having the ability and opportunities to interact socially, and to develop relationships with others enabling their continuing well-being.

Pertinent to this thesis are the prevailing ageist attitudes in society which provoke stigma, stereotypes, lack of engagement by others with older people, and by association, negative perceptions of residential aged care. Commissioner Briggs challenges all misplaced perceptions of people with advanced dementia in her assertion that:

> *Understanding and respecting the unique life experiences of people accessing care is affirming. The message it sends is—you are seen, heard, and you matter. Everyone has their own needs, preferences, values, feelings and expectations. These should be put at the centre of a person's experience of care… making a person feel valued for who they are can protect them from feeling like a passive recipient of care, and support them to feel recognised as a person with a past, a present and a future (Royal Commission into Aged Care Quality and Safety 2021a, p. 31)*.

Briggs' declaration establishes that the basics of care are focused on the personhood of all who live in residential aged care, and that effective care values their voice. Each person has the right by virtue of their presence in the world to be affirmed in their personhood with value, dignity and respect. This thesis demonstrates the person's creative and instinctive capacity and capability to communicate. It is for others to be attentive to listen, observe and appreciate their communication. Every aspect of their being, including the various ways the person communicates, requires recognition and responsiveness to their personhood from those who have care responsibilities. Commissioner Briggs strongly advocates for understanding the person's lived experience and perspectives. Yet people with advanced dementia, their voices and lived experience have been ignored in research studies. For example, an Australian scoping review affirmed the use of innovative qualitative methods to include people with advanced dementia, yet identified only four qualitative studies with some participants with advanced dementia, and no studies entirely with this group (Phillipson & Hammond 2018). The research described in this thesis contrasts with previous studies by positioning people with advanced dementia as central participants and contributors in articulating their lived experience and sense of self. With its focus on developing praxis, this thesis advocates for a focus on the voices of people living with advanced dementia and their lived experiences, so that their lives may be as fulfilling and meaningful as possible.

1.4 Positioning of Researcher: Theological Reflection and Ethical Reflexivity

This research differs from previous research by exploring the lived experiences of people with advanced dementia from their perspectives and according to what is important to them, rather than primarily from the perspectives and input of family and staff. As will be expanded in Chapter 4, this approach is founded on my Christian ontological position that respects the value and inclusion of each person. My epistemology is then formed by focusing on inclusion and creating opportunities for people to participate and contribute to their fullest. This ethos particularly includes those who may be presumed as incapable and mute, and thereby marginalised and excluded.

Theological Reflection

As a significant and usual aspect of my praxis as a chaplain I engage in the process of theological reflection. My theological reflection is my approach to perspectives and positioning, my own and those of others, and the ways these aspects together inform praxis. My establishing of a theological basis for this thesis guides my perspectives and positioning towards each person and my theological reflection in each encounter:

> The person as being created in God's image and in so being, as loved and valued by God (Woźnica 2019); in peaceful relationships with others and self and worthy of the respect and responsiveness of others (McFadden, S & McFadden 2012, pp. 126-7); living the paradox of being both frail and strong, as limited and yet capable (Paver 2006, pp. 72-6); continuing to live one's storied-life and become in each encounter and activity (Hudson 2012); being recognised as a participant in an interdependent reciprocal community (Byrne 2002; Miller-McLemore 1996); and being responded to as a citizen amongst other citizens with rights, opportunities and contributions in the ordinary experiences of daily life (McFadden, S & McFadden 2012, p. 178).

This integrative approach is aligned with that of Paver (2006). In Chapter 4 there is an outline of Paver's paradigm of theological reflection, which he described as including "method, insight, action, theology and critique" (p. 42). At various points in this thesis I outline how this process is threaded through this research praxis.

These foundational beliefs are intrinsic to this study. They are very much aligned and interwoven with the principles of psycho-social spiritual well-being for each person as being multi-dimensional, including:

> The person being acknowledged for personhood with respect and dignity (Hennelly et al. 2021; Zeiler 2014); enjoying interaction and relationships with family and others (Hennelly & O'Shea 2022; Kontos, P, Miller & Kontos 2017; Walmsley & McCormack 2017); having capabilities and capacities, and becoming in the moment and as a citizen in the ordinary domestic activities though the day (Brannelly 2016; Gjernes & Maseide 2020); participating with one's agency and identity in making a contribution in interdependent community (Batra et al. 2016; Watson 2019); participating in activities of personal interest and preference (Pöllänen & Hirsimäki 2014; Schneider et al. 2019); continuing one's storied-life (Berendonk & Caine 2016; Vigliotti, Chinchilli & George 2019).

My theological reflection connects me with my own and others' lived experience. Theological reflection also connects with my ethical reflexivity in everyday life, including in my research praxis and throughout this thesis.

People living with advanced dementia are vulnerable due to varying abilities to protect and pursue their own interests. Their vulnerability necessitated developing ethical requirements for the purposes of their protection and to emphasize their special needs in care settings (National Health and Medical Research Council (NHMRC) 2018). Due to the vulnerability of the central research participants, the process of University Human Research Ethics Committee (HREC) approval was rigorous and lengthy, ensuring that my protocols and procedures were thoroughly considered and would be carefully implemented. However, it was still important to articulate and adopt an ethical responsiveness and reflexivity to guide my research praxis. Ethical premises undergird this research at every stage, therefore participation of people with advanced dementia, and indeed of all participants, was based throughout on building respectful, collaborative, reciprocal, trusting and friendly relationships. Ethical accountability required critical awareness of my embodied enactment in word and action, and self-reflexivity in the moment and retrospectively (Rogers 2020). Personhood and person and relationship-centred principles, therefore guided how I built relationships and interacted with each person in the field study (Nolan et al. 2002; Sabat 2003).

Ethical reflexivity: trustworthiness as rigour

In establishing a research trustworthiness as rigour throughout the research I referred to the text of Koch and Harrington (1998). Their work recommends that rigour be demonstrated by the researcher in the incorporation of a reflexive account as a research audit trail to show what was going on in the researcher and research process. This reflexivity trail is outlined as:

Chapter 1, 2, 4-5:
Positioning myself as researcher (Koch & Harrington 1998, p. 886);

Chapters 2-3:
Surveying a range of literature, including moral socio-political contexts; positioning of the literature (Koch & Harrington 1998, p. 887);

Chapter 4:
Establishing my ontological and epistemological positioning initially as a benchmark for my ethical practice throughout the fieldwork and thesis; recognising the data as a co-construction of myself as researcher and research participants (Koch & Harrington 1998, p. 887);

Chapters 5, 6-8
Questioning my own positioning as praxis as engagement and relationality with participants and others throughout the fieldwork; showing internal logic as decisions are reflexively discussed;

providing alternative praxis and representations as integral part of fieldwork; producing a many-voiced account of central and other participants (Koch & Harrington 1998, pp. 888-9);

Chapters 9-10
Producing a research product with applicability for transforming research and practitioner praxis (Koch & Harrington 1998, p. 886).

This reflexivity trail is well signposted through the thesis for the reader.

1.5 Research Design

Qualitative methodology

The research study's design was grounded in the qualitative paradigm, exploring the diverse and detailed lived experiences (van Manen 1990) of people with advanced dementia. Ethnography was chosen because of its capacity to explore the lived experiences of people in their natural setting and unique cultural context, and to enable the immersion of myself as researcher into the lives of participants as individuals and in groups (Liamputtong 2013; O'Reilly 2009). Ongoing assent of people with advanced dementia occurred through the process consent method (Dewing 2002, 2007). I 'shadowed' participants (Czarniawska 2007), that is, I was 'alongside' people with advanced dementia[3], developing trusting relationships first and foremost and being involved in interactions and activities with them.

Research setting

The fieldwork phase occurred in Adelaide, South Australia during late 2017 – mid 2018. The setting was two aged care homes in a medium-sized aged care organization, approximately 80 residents and 100 staff, and 120 residents and 150 staff respectively. The research took place over six months, first in one and then in the other home.

Research questions and original contribution to knowledge

Research pertaining to the voice of the person with advanced dementia has usually evidenced a particular aspect of the person's capabilities and capacities regarding topics related to their voice, for example: their visual acuity (Chriqui et al. 2013), embodied language (Eisenmann et al. 2016), continuing identity, agency and storied-life (Kontos, P et al. 2017), and interaction and relationships with others (Walmsley & McCormack 2017). These studies combine to provide a broad landscape of research through which to view the person's voice. Undertaking an integrative literature review (Whittemore & Knafl 2005) and compiling themes, honed the focus of this study. This integrative

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[3] Each person had a diagnosis of dementia with high care needs, verified by the Clinical Coordinator (see Glossary) at each aged care home. Each person had assented to interacting and being engaged with me as the researcher, and their substitute decision maker had given informed consent for this involvement in the research project.

review discerned that there was a lack of research literature regarding a holistic and integrated understanding of the voice of the person with advanced dementia. Specifically, scant attention has been given to how the person voices their lived experience as an aspect of their social, emotional and spiritual dimension. My thesis responds to this gap in knowledge by seeking to present a more detailed understanding of the voice of the person with advanced dementia. More specifically the thesis considers how and why and in what circumstances the person expresses and enacts their voice. Reflection on personal and professional experiences and attention to the gaps identified in the integrative literature review (see Chapter Three), prompt the following research aim:

- to develop a holistic and integrated understanding of the voice of the person with advanced dementia in residential aged care, and how their voice may be promoted;

and the following research questions:

- What are the ways the older person with advanced dementia expresses or enacts their voice?
- What enables the voices of older people with advanced dementia in residential aged care?

My original contribution to knowledge lies in developing an understanding of the voice of the person with advanced dementia, how and why they express and enact their voice in their lived experience, and the significance this has for them and others who offer care and share their lives.

My original contribution is expressed in the objectives of this thesis which are:

- positioning people with advanced dementia as central participants and contributors;
- exploring their lived experiences in voicing themselves, and the significance this has for them;
- examining how the facilitation of family and staff members in a wide range of roles promotes their voices;
- exploring how the person's voice relates to their spiritual dimension, and how spiritual care praxis may promote their voice.

My intention is to write this thesis for a wide audience, such as formal service providers from a range of disciplines, and informal care providers in residential aged care and community settings. So my writing is necessarily eclectic. The strong emphasis on the image of 'created in God's image' alongside personhood, recognises this wide readership. This thesis contains diverse previous literature, methodology, methods, and findings, with the resultant praxis implications. My hope is that its content might connect meaningfully and reflectively with readers of various beliefs, disciplines and previous experiences and attitudes.

Form of the thesis

Beyond this Introduction the thesis has nine chapters.

Chapter 2 - ‘The Context’: provides an overview of the contextual literature on international, national, and local residential aged care. I also examine the societal context of residential aged care, and how perceptions and positioning frame a social imaginary of people living with advanced dementia which either positively facilitates, or negatively inhibits their voices.

Chapter 3 - ‘The Literature Review’: begins to define the voice of the person more generally using philosophical and theological theory, and provides an initial working definition of the voice of the person in the context of this study. The chapter then develops an integrative literature review of specific themes of voice in research from 2011-2022 and identifies gaps in knowledge that inform the research questions and objectives.

Chapter 4 - ‘Developing the Methodology’: outlines the conceptual and theoretical scaffold on which the research project was built, firstly from personal and professional experiences, and then my foundational ontology and epistemological and theological reflection and ethical reflexivity. The chapter articulates the overarching qualitative methodology and specific ethnographic design.

Chapter 5 - ‘Translating Methodology into Practice’: narrates the research journey consistent with the methodology, from its inception and planning, through gaining consent from the residing participants, to my participation in and departure from the two aged care homes. I describe the methods used for the co-construction of these data and their subsequent analysis.

Chapters 6 to 8 are the analysis chapters responding to the two research questions.

Chapter 6 - ‘Voice in Forming Relationship’: details the findings compiled from the episodes of one-to-one interactions-conversations and participant observation in groups. Exemplars of participants represent the combined data set and explicate the themes developed through analysis.

Chapter 7 - ‘Voice in Developing Relationship’: describes the provision of spaces and relationships as the context for the person expressing and/or enacting their voice agency, identity and storied-life through their voice, elaborating on remarks made by family during interviews with them, as well as staff comments and practices that facilitate the voice of the person with advanced dementia.

Chapter 8 - ‘Voice in Deepening Relationship’: the final chapter to present empirical findings focuses on people expressing and enacting the emotional and deeper expressions of their voice in trustworthy and attentive relationships. The person articulates their connections with who and what continues to be an important aspect of their lived experience. I also explore the significance of having their voice, as an aspect of the person’s spirituality and well-being.

Chapter 9 - ‘Discussion on The Learnings’: discusses the three analysis chapters above in light of the research questions, as well as broader praxis implications and applications for people living with advanced dementia, and those responsible for providing care services within residential aged care. I also respond to the findings by formulating an expanded definition of the voice of the person with advanced dementia, and discerning a way forward in praxis that might be transformative.

Chapter 10 - ‘Conclusion’: brings together the threads of the thesis, responding to the research objectives. It outlines the limitations of this research and recommendations for undertaking research with people with advanced dementia, and also potential future research directions.

CHAPTER 2 THE CONTEXT

Introduction

This chapter provides the context for the thesis, reviewing and examining the global, national and localised residential aged care scenes, and presenting statistical information within each of these contexts. Given the limited attention that has been given to understanding the person with advanced dementia I critique several ways of defining and describing the person. Supported by the grey literature, I then consider how people with advanced dementia are perceived within society. Here I explore the dichotomised perspectives and presumptions about people with advanced dementia.

This chapter traverses the various contexts which define and describe the person with advanced dementia in five main sections: 2.1 ‘Global Statistics and Response’, outlines global statistics, concerns and agendas; 2.2 ‘Australian Statistics and Response’, presents Australian statistics and Government’s reforms to policies in response to the Australian Royal Commission’s Final Report into Aged Care Quality and Safety; 2.3 ‘Towards a Definition and Description of the Person with advanced dementia’, provides practical understandings to guide this thesis within the biomedical and psycho-social paradigms; 2.4 ‘Residential Aged Care in Australia’, describes and evaluates the residential aged care setting, historical and current perceptions, relevant findings of the recent Royal Commission, and current revised measures of care quality; 2.5 ‘Societal Perceptions and Positioning’, depicts the negative and positive social imaginary of people with advanced dementia influencing attitudes and outcomes.

2.1 Global Statistics and Response

Statistics for dementia confirm its prevalence across the globe and highlight its impact on significant numbers of people who live with this disease, their families and the wider community. World Health Organization (WHO) statistics indicate the magnitude of dementia globally with around 55 million people with dementia, and nearly 10 million new cases every year (WHO 2023). In epidemiological surveys statistics are projected to rise exponentially, to 75 million people living with dementia in 2030 and 132 million by 2050 (Prince et al. 2015; WHO 2021). The WHO ranks dementia among the top ten causes of disability and death worldwide (WHO 2021). In response, the WHO has designated dementia “a public health priority”. As its public health response, the WHO launched the Global Action Plan 2017-2025, to provide a pro-active blueprint of measures covering a range of broad strategies (WHO 2017). These include “establishing dementia-friendly initiatives; reducing the risk of dementia; providing timely diagnosis, treatment and care; developing public information systems; supporting dementia carers; researching and innovating” (WHO 2017, p. 3). In this plan the WHO emphasises the human rights of all people with dementia and their carers to equity of access to resources for their empowerment, engagement, prevention, cure and care, as founded in evidence-based practice.

2.2 Australian Statistics and Response

The Australian government has endorsed the WHO Global action plan (WHO 2017) and named dementia a national health priority. In 2022 dementia was the second leading cause of death in Australia. By 2030 it is anticipated that up to 550,000 people will have the disease, and this will increase to 1,000,076 people by 2058 (AIHW 2021b; NATSEM 2018). Epidemiological and economic data for dementia globally and nationally reinforce the standpoint that dementia places a major burden on health and financial systems. This disease impacts the social well-being of the person and their informal caregivers (NATSEM et al. 2017, p. 36). The descriptor of “burden” has become a referring definition of dementia. “Burden of disease” is an epidemiological term referring to the quantified impact of the disease on years of life lost through disability and death for the person and their informal carers, extrapolating to the general population (AIHW 2021c).

The Australian government, with the Department of Health and Aged Care, and in consultation with key stakeholders, is developing The National Framework for Action on Dementia which is expected to be completed in 2023 (AIHW 2023). In prioritising dementia as a public health issue, the Australian Commonwealth government has pro-actively invested in both the policy and funding framework. For example, it has legislated standards for multiple aged care programs, and funds the means tested subsidised residential aged care program (Department of Health and Aged Care 2021). The National Dementia Support Program (NDSP) is an Australian Government initiative to fund information, education programs, services and resources. The policy and funding framework is now also responding to the Final Report of the Australian Royal Commission into Aged Care Quality and Safety, February 2021 (Section 2.3.3). The Australian government has articulated its commitment to the Royal Commission’s final report with a proposal for broad ranging reforms, fortified by a new Aged Care Act and the 2021-22 Federal Budget of $17.7 billion (Commonwealth of Australia as represented by the Department of Health May, 2021, p. i).

In response to the Royal Commission’s recommendations the Australian government and its departments are currently involved in a process of developing policy documents through consultation with consumers and advocacy groups. Part of the aged care reforms is the newly released Code of Conduct and the Charter of Rights (Aged care Quality and Safety Commission 2021a), based on the revised Aged Care Standards (Aged Care Quality and Safety Commission 2022b), and the Serious Incident Report Scheme (SIRS) (Department of Health and Aged Care 2022), with more initiatives to follow. The consultative Aged Care Sector Committee of key sector stake-holders has instigated A Quality Vision for Aged Care (Aged Care Sector Committee 2020) which outlines how its broad vision aligns with The Charter of Rights and the revised Aged Care

Quality Standards. This Vision statement elaborates on the characteristics of quality services as: safe, effective, inclusive, caring, transparent, accessible, responsive and well-led (Aged Care Sector Committee 2020). These initiatives echo the WHO's Global Plan.

There is no doubt as to the upheaval occurring in the Australian aged care sector in this period. We wait to see how the reformative processes and policies being implemented, proposed, and yet to be formulated will transform the presently deficient systemic situation. Many in Australia concur with the statement of Commissioner Briggs, in the hope that all older people are able to enjoy their last phase of life as "hold[ing] as much promise and meaning as all other stages of life…as a time for living, not biding time" (Royal Commission into Aged Care Quality and Safety 2021a, p. 32).

The following section addresses the complexity of how dementia is defined, diagnosed and described in its various stages and types, and particularly in the advanced stage.

2.3 Towards a Definition and Description of dementia

Dementia is described broadly as a collection of symptoms caused by disorders affecting a person's brain. It is not one specific disease, but an umbrella term describing a collection of symptoms from a range of conditions that cause parts of the brain to deteriorate progressively. Dementia affects the person's thinking, behaviour and their ability to perform everyday tasks (Moyle et al. 2015; WHO 2020). The different forms of dementia include Alzheimer's, vascular dementia, Lewy-body dementia, and frontal lobe dementia, with Alzheimer's being the most common. The boundaries between different forms of dementia are indistinct and a person may experience mixed forms (Dementia Australia 2020).

Over previous decades the scope of research and services regarding dementia particularly, have emphasised the bio-medical paradigm (Behuniak 2011; Gerritsen, Oyebode & Gove 2018; McParland, Kelly & Innes 2017). This bio-medical focus has responded to people living into advanced age, with the associated global rise in the number of people diagnosed with dementia and other diseases, and the bio-social needs of each person and their family. The bio-medical model of the disease provides clearer diagnosis, verifies its symptoms, and the efficacy of clinical and other interventions (Collier 2013, pp. 17-8). As such, the bio-medical approach to care assists in alleviating "the distress and suffering" of the person with dementia through apt interventions, such as medications to relieve anxiety or pain (Reisberg et al. 2006, p. 83). However, the bio-medical paradigm of dementia operates within the frame of diagnosis, the increasing deficit and decline of the person's cognitive and physical capacities, and a discourse of loss for those living with advanced dementia (McParland, Kelly & Innes 2017; Pieper et al. 2016). Within the bio-medical realm the diagnosis of dementia often seems to be an isolated factor, separated from the person living with this condition. Some academics critique that the disease takes precedence while the person with the disease becomes the object being overlooked (Brannelly 2011; Kelly 2014).

This impression is reinforced by the ways in which dementia is defined, for example the WHO defines dementia as:

> *A syndrome in which there is deterioration in cognitive function beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not affected. The cognitive impairment is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation (WHO 2020).*

This definition seems to depersonalise the disease, even while identifying the various aspects affected in the person. But significantly the definition recognises that “consciousness is not affected”. Indeed researchers in the field have suggested that consciousness means far more than the person simply existing by their breathing per se, and that the person retains the capacity to be aware and to take notice of their environment and others, and the capability to respond through to the advanced stage of dementia (Clare, L et al. 2013; Rice, Howard & Huntley 2019).

Database searches of research regarding the person with advanced dementia have revealed a predominantly bio-medical paradigm (see Chapter 3). As the person moves through the dementia stages their care becomes increasingly focused on clinical-medical management of symptoms, including pain and other physical conditions, and especially in their end-of-life care (Lee et al. 2017; Majic et al. 2012). Yet in this diagnostic approach there may be an implicit positioning of the person, pathologizing or problematizing their “behaviours” as a symptom of the disease, rather than looking for other possibilities based on their personhood and identity (Blythe et al. 2009; Bourbonnais & Duchame 2015; Majic et al. 2012). According to some commentators the bio-medical focus on dementia has morphed to a bio-psycho-social one (Cahill 2018).

Table 1 (below) outlines the progressive stages and effects of dementia according to the WHO. The WHO schema covers the bio-psycho-social indicators, that are often used with other signs to determine the stages of dementia.

Table 1 Stages of Dementia (Adapted from Dementia Fact Sheets WHO 2020)

Early stage: often overlooked, because the onset is gradual. Common symptoms include:
• Forgetfulness • Losing track of the time • Becoming lost in familiar places.
Middle stage: the signs and symptoms become clearer and more restricting including:
• Becoming forgetful of recent events and people's names • Becoming lost at home • Having increasing difficulty with communication • Needing help with personal care • Experiencing behaviour changes, including wandering and repeated questioning.
Advanced stage: near total dependence and inactivity. Memory disturbances are serious and physical signs and symptoms more obvious. Symptoms include:
• Inability to communicate • Unaware of time & place • Difficulty in recognising relatives & friends • Needing total assistance with self-care • Difficulty walking, to immobile and inactive • Experiencing behaviour changes that may escalate and include aggression

The WHO schema presents the three stages in terms of the descriptors of the person’s decline over time and their increasing deficits. The course of the disease implies the person’s need for increasing support and eventually substantial care. In developing an indicative course of dementia, the table is assumed to define how a person traverses the various stages. The person’s life trajectory is shaped by a diagnosis of the syndrome and a generic symptomatology (Stacpoole et al. 2015).The language can become prescriptive of the progression of decline in the disease process. People at any stage are often considered a homogeneous cohort (Ludwin & Capstick 2015), but particularly in the advanced stage of dementia. The view that still pervades public thinking and care provision in the advanced stage is of the person having prescribed limitations, inabilities and decline, as well as “behaviours”. The person is depicted as being more likely difficult to manage and prone to aggression, rather than according to their individual characteristics, capabilities and capacities (Ludwin & Capstick 2015; van der Steen et al. 2017). People in this stage are widely deemed, even by a leading advocacy group, to be inactive, unable to communicate or initiate interaction, and needing homogenous care strategies, particularly for their “behaviours” (McParland, Kelly & Innes 2017; Sabat et al. 2011; USA Alzheimer's Association 2020). Such a stance can predetermine a person’s limitations, including their ability to express themself, and inhibit their voice.

Several terms are used for the final stage of dementia, including ‘end stage’, ‘late stage’, ‘terminal’, ‘advanced’, ‘profound’ and ‘severe’. ‘Advanced’ or ‘severe’ dementia seems to be used most often in literature such as research publications and reports of government or peak bodies. In this thesis I have chosen to use the term ‘the person with advanced dementia’, of the person living in the late stage of the disease, to recognise their possible limitations and also their potential capabilities and capacities. A predictive course of dementia tends to elaborate on it being a degenerative and terminal disease (Johnson et al. 2009; van der Steen et al. 2017). However, the diagnosis of when a person is in the advanced stage lacks precision, with little consensus (Brown & Tolson 2020; Sampson 2010; Yeo et al. 2016). In the residential aged care setting a specific diagnosis of advanced dementia is not usually applied clinically and does not usually appear on the person’s record. Rather a diagnosis of “dementia”, sometimes a specific type, and assessed high care needs in each care domain is documented for the person. People may live in this stage for several years and some do not have a clearly defined, or only a brief, palliative phase (van der Steen et al. 2017). Diagnoses are often contingent retrospectively on a person dying within a three-month to three-year period (Brown & Tolson 2020). However, the person’s life trajectory remains uncertain and some people live for many years with advanced dementia (van der Steen et al. 2017).

People in the advanced stage have complex and changing holistic needs that necessitate holistic understanding and assessment to guide the process of their care in all aspects of their person. In the Introduction (Chapter 1.2) the definition for advanced dementia developed by Alzheimer Scotland (2019) in partnership with the Fair Dementia Care Commission was provided. This definition was formulated in response to the recognition that people with advanced dementia and their families and carers, require fair provision and access to holistic services appropriated to their needs. In the past, due to the absence of a definition, the needs, concerns and issues faced by the person into the advanced stage of dementia have not received specific attention, inhibiting the development of, and the provision and access to, appropriate assessment and services. I use the broad-ranging definition of Alzheimer Scotland (2019) for advanced dementia in this thesis. This definition considers the general ways in which advanced dementia affects people and also that it is a unique experience for each person. Care provision is conceived as a balance between the various aspects of the person. Each of these aspects shape the person’s lived experience, since advanced dementia is not just a disease of brain pathology, but also a bio-psycho-social-spiritual phenomenon. However, as a definition it needs detailed description about what this means in each person’s lived experience of advanced dementia. Rather than assuming a prescriptive diagnosis, this thesis’ approach has principally acknowledged the personhood and diversity of people with advanced dementia. This has meant my forming a unique, relational and descriptive understanding of each person living with advanced dementia (Ludwin & Capstick 2015). This perspective prompts nuanced understandings that respond to and care for each person in ways that promote their care holistically. Such care optimises their comfort and sense of well-being and promotes their best possible living and end of life experience. The recognition and encouragement of their retained unique capabilities and capacities enhances their ongoing quality of life and well-being across the various dimensions of their personhood in this advanced stage of their life. Certain societal perceptions are now critiqued as they relate to and affect the person and their voice.

2.4 Theoretical Underpinnings: Societal Perceptions and Positioning

The ways in which others and society more broadly perceive and position the person with advanced dementia within their social and cultural contexts, affects the person, their family and formal care givers (Kinghorn 2016). These perceptions configure as societal images and narratives that are socially-constructed and socially-maintained. The images and narratives become inter-twined with the scientific evidence that is circulated about people who are ‘frail’ (Pickard 2014). Social constructions affect how interactions with people with advanced dementia, can both limit or expand their lives.

A perusal of the literature relating to people with advanced dementia within western society reveals two dominant contrasting perceptions. The two extremes are the person in deficit, decline and marginalised; or, in contrast, still communicative, capable and included within relationships (McParland, Kelly & Innes 2017). Higgs and Gilleard (2017) use the concept of ‘the social imaginary’, coined by Greek-French philosopher, Castoriadis in 1987 to explain the power of these perceptions. Castoriadis (1987) considered the social imaginary to be intrinsic to the functioning of society and social institutions. Higgs and Gilleard (2017, p. 371) suggest that the social imaginary may be defined by how it operates in society whereby:

- social meanings and representations attach to social institutions and a person and cohorts of persons inhabiting them according to age categorisations;
- social meanings and representations become symbolised, narrated and generalised;
- social meanings and representations take on the form of social norms and affect an individual’s identity and role in the perceptions of others (Castoriadis 1987).

Australian feminist social philosopher, Gatens (1996), posits a similar notion in “the cultural imaginary”, commenting on the way social bodies and their histories are characterised through pre-conceived images and language. This process of imagining social bodies “determine[s], in part, their value, status, and what will be deemed their appropriate treatment’’ (Gatens 1996, p. viii). The social-cultural imaginary influences the ways in which the person and/or persons are positioned by others. Positioning theory understands that the social construction of certain cohorts of people determines the ways they are defined, described, related to, and participate or not within social and societal contexts (van Langenhove & Harré 1999). Thereby this positioning by others impacts the lives of people with advanced dementia, either positively or negatively, directly and indirectly. The effect of the negative imaginary may lead to ageism, fear and stereotypical subaltern images of people with advanced dementia, perpetuating a narrow world view. The next sub-sections consider these two world views and how they affect the person with advanced dementia, beginning with the negative imaginary.

Negative perceptions and positioning: ageism, stigma and stereotypes

Literature supports the notion that society constructs and generalises features of old age as ‘social and cultural signs’ (Laws 1995 p. 113). The ‘fourth age’ as life’s end phase is often envisaged as lacking promise, reciprocity and engagement, and of ‘ageing without agency’, contrasting with the ‘third age’ of ‘choice, autonomy, self-expression and pleasure’ (Gilleard & Higgs 2010, p. 125; Higgs & Gilleard 2015). This dichotomy marginalises the assumed incapacitated oldest, from the younger capable generations (Birt et al. 2017). This definition suggests an ageist stereotype. Perhaps this perception is due to others’ reactions of uncertainty and fear of the loss of one’s own autonomy and independence (Howarth 2014; Lloyd et al. 2014). Ageism “is arguably one of the last forms of open and socially acceptable discrimination” (de Medeiros 2019, p. 799). The fourth age becomes the scapegoat for tragedized thinking, internalised and perpetuated by policy wielding governments and the media (Higgs & Gilleard 2015; McParland, Kelly & Innes 2017). A specific example is the Royal Commission’s finding that successive governments have inadequately funded aged care and thus impeded the provision of quality care (Royal Commission into Aged Care Quality and Safety 2021c, p. 9). The mass media plays a significant role in portraying older people as “the object of pity or as the victim of scandalous practices” (Westerhof & Tulle 2007, p. 241). Humour, and the careless use of language in the media contribute to negative stereotypes (Sabat et al. 2011). A radio presenter, when discussing “schoolies week”[4], joked that he was “getting more like a droolie than a schoolie” (Smyth 2015).

Theory has posited that the status of the person with advanced dementia is influenced by being reassigned into ‘the fourth age’ (Lloyd et al. 2014; Rumbold 2006), in which people are presumed no longer to engage meaningfully, actively and successfully in society (Higgs & Gilleard 2017). People with dementia are described sometimes as ‘the living dead’ or ‘zombies’ (Behuniak 2011), and perceived in the advanced stage as only a shell without a sense of self (Kitwood 1997; McParland, Kelly & Innes 2017). The notion of the burden of dementia placing an unacceptable and even untenable demand on resources may also intensify negative connotations of people with dementia (Grenier, Lloyd & Phillipson 2017). In a society where resources, individual and public, are “scarce”, these are more likely to be allocated to those who have lived and aged successfully as active and well (Howarth 2014; Rumbold 2006). The epidemiological statistics are presented within an “apocalyptic consequence causing alarm, fear and trepidation” (Barclay 2014). The WHO published a pamphlet for its 2017 Global Action Plan possibly symbolising its priorities. This pamphlet illustrated a large green brain, a graph of the costs rising exponentially, and a silhouette

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[4] “Schoolies Week” is an annual week-long celebratory event for school leavers held at the end of the school year throughout Australia.

of a person with a walking frame receding into the background, inferring the dominant subjects of the plan as the affected brain and economics rather than the person (WHO 2017). These reactions diminish each person with advanced dementia who is deemed to be in the 'fourth age', of their humanity and value. This perspective further stereotypes and stigmatises them, and silences their voice (Birt et al. 2017; Higgs & Gilleard 2015; McParland, Kelly & Innes 2017; Volicer 2016).

With her lived experience of disability, Wendell (1996 p. 85) claims that negative stereotypes and stigmas are directly related to aspects of the body "that are feared, ignored, despised, and/or rejected in society and its culture" . People with lived experience of dementia write of the lack of understanding and knowledge of others in relating to a person with dementia at any stage (Bryden 2015, 2018; Swaffer 2014, 2016). Stereotypical attitudes towards people with dementia position them as passive actors, without status, ostracised from relationships, lacking opportunities to socially interact, leading to "prescribed disengagement" (Evans-Lacko et al. 2019, p. 26; Swaffer 2016, p. 158). "Prescribed disengagement" is Swaffer's term for the doctor's counsel to leave her job and community involvements when she was first diagnosed with dementia.

The 2019 World Alzheimer's Report followed up the findings of its earlier 2012 report, ascertaining that stigmatisation had not reduced during the previous decade (Young, Orange & Lind 2019, p. 17). Stigma assumes and emphasises the loss of the capabilities and capacities of people with dementia. If a person living with dementia from an early stage is stereotyped and thereby stigmatised, then their presumed deficits and decline, including their inability to communicate meaningfully, are inculcated long before they reach the advanced stage (Shakespeare, Zeilig & Mittler 2017). Whether the person retains their personhood is compromised by the assumptions of family and formal caregivers, that personhood is based on one's competencies (Hennelly et al. 2019, e86) that diminish or cease with one's cognitive capacities (Hennelly et al. 2021). Thereby others position the person in ways that undermine their dignity and well-being and effectively silence them (Sabat & Lee 2011; Swinton 2012a, p. 89). The effect of stigma is "dehumanising and anonymising, and discounts the voices of people and the actualities of their lived experiences" (King 2021). The person is deemed to be without personhood, unable to voice coherently, and to communicate in the advanced stage, and is devalued, marginalised and ignored.

Positive perceptions and positioning: personhood, interdependence, citizenship

There is a need to discern fresh and individualised theoretical perspectives for each person (Ludwin & Capstick 2015), rather than indeterminate generalisations based on their dementia diagnosis. In this thesis I argue for nuanced and individualised perceptions and responses to people living with advanced dementia, based on an understanding of their personhood and lived experience. I now describe an alternative social imaginary of the person living with advanced dementia as an affirmation of positive social perspectives and positioning. The alternative societal perspective positions each person with dementia, including those with advanced dementia, as a person of worth, respected, valued and contributing in relationships with others (Canning, Gaetz & Blakeborough 2020; Kontos, P, Miller & Kontos 2017; Kontos, P et al. 2021; McFadden, S & McFadden 2012). This social imaginary recognises the person as able to participate in their own way and make their contribution to relationships and community. This radical ontology reframes people with dementia, from diagnosis into the advanced stage, as equal and capable subjects and contributors to social settings (Kontos, P & Grigorovich 2018).

There has been a growing commitment to regenerating a common humanity and well-being for all older people, particularly those whom others may marginalise or silence (Basting 2020; McFadden, S & McFadden 2012; van Amerongen 2019). As Dutch care practitioner van Amerongen (2019) asserts in her Ted Talk, every person, including people living with advanced dementia, is a social being desiring and needing “fun”, “meaning” and to belong in society. Recognition and explicit validation by others of the personhood, inter-dependence and citizenship of the person with advanced dementia, confirms their continuing worth, significance, belonging, and fullness of life.

Acknowledgement of the theories and praxis of personhood, and more recently a focus on the theories of the interdependence and citizenship of the person with advanced dementia, frames the contextual lens for this section. Firstly, there is a discussion of the historical roots that initiated a positive social imaginary, emphasising the recognition and preservation of the personhood of people with dementia, particularly moderate to advanced dementia.

Historical roots of a positive social imaginary - theories of personhood and positioning

Compassionate and respectful relationships as the essence of caring have historically and recently often been sadly lacking in relation to the provision of services to people with advanced dementia. In the mid to late 1990s dementia practitioners, Goldsmith (1996), Sabat (1994), and Kitwood (1997) were critiquing the underlying suppositions and practice of residential and community aged care. Goldsmith (1996) emphasised that people with dementia are not only disempowered by the disease, but also by the attitudes of others and society generally, and various forms of institutionalisation. However, Goldsmith’s research verified that consumers of care, including those “in advanced states of dementia, are able to express preferences and reflect subjectively” (Goldsmith 1996, p. 161). Recognising each person’s form of communication, Goldsmith developed flexible individualised approaches to care and research.

Kitwood’s ground-breaking work as a practitioner-researcher and author in residential and community care, responded to the stereotyping and ‘malignant pathologizing’ of people with dementia. He envisaged a theory of radical reframing from prejudice to personal and cultural change “to recognise men and women with dementia in their full humanity” (Kitwood 1997, p. 7). While Kitwood (1997) defined personhood as being bestowed upon the person with dementia by others, he also emphasised the relational aspects of personhood. Kitwood developed his theory of human behaviours and interactions and their effects on people with dementia, identifying the ways other people validate or violate the person. This framework emphasised that the positioning, attitudes and approach to care by others are strong determinants of how a person with dementia experiences and expresses their identity, and responds to others and their environment (Kitwood 1997, p. 7). Kitwood's 'malignant social psychology' categorised the negative behaviours of others such as: silencing, ignoring, trivialising, or subverting them from expressing their identity (Kitwood 1997, pp. 46-7). Such behaviours denigrate the person with dementia and diminish their ability to interact and experience life positively. Kitwood proposed that each person needs moral and pragmatic support in and through relationships. He devised a regime of the affirming behaviours of others towards the person with dementia, including recognising the person by their name and their unique characteristics; acknowledging and providing for their needs, preferences and choices; and being open to receive from the person (Kitwood 1997, pp. 90-2).

Sabat, a neuropsychologist with a long history of research with people with moderate to advanced Alzheimer's, determined that they have continuing cognitive, emotional and social abilities and capacities (Sabat 2006; Sabat & Lee 2011). Advocating for the recognition of each person's intact abilities (Sabat 1994), Sabat recommended "creating research partnerships" with them (Sabat 2003). Through his extensive research, Sabat continued to develop the theory of 'the positioning by others'. Sabat highlighted the ways others define and a behave towards the person either negatively or positively that affect the person and their responses to others. Malignant positioning excludes, while on the contrary affirmative positioning facilitates the person being included and maintaining a positive sense of self (Sabat 2002; Sabat & Harré 1999). In summary, these early pioneers developed theories borne of their lived experience with people with dementia into the advanced stage. They emphasised the ongoing recognition of personhood and the provision of person-centred care, appropriated to each person through the attentive listening and affirmative responses of others. Their work advocated for the person in the various stages of dementia, particularly in the advanced stage, to be acknowledged, validated and supported in their personhood, making it feasible for them and their voice to be recognised.

Later practitioners have developed this pioneering work further, into perceptions and practices promoting communication in the care setting. Theorists have expanded on Kitwood's initial conceptualisation of personhood to further clarify its implications for relationship-centred care (Nolan et al. 2004; Nolan et al. 2008). There has been elaboration on the verbal and non-verbal cues that people with dementia in all stages express, enact and perceive from others in their environment (Killick & Allan 2010). As will be discussed in Chapter 3 researchers have continued to identify various capabilities in the person with advanced dementia. However, as discussed above, despite this work in developing knowledge of the person in the various stages of dementia the person with advanced dementia continues to struggle to have their personhood recognised.

Personhood - embedding theory in praxis

Personhood is intrinsic to each human being, as they are present within life's experiences and relationships. The fundamental presumption of this thesis is that each person with advanced dementia is recognised "in their full humanity", their personhood, with their right to the respect and recognition of others as unique and valuable (Shakespeare, Zeilig & Mittler 2017).

Although the concept of personhood is not based on the same premise, it is not far removed from the Christian theological concept of the person being created in the image of God. The creation of human-kind in God's image is a Judaeo-Christian biblical principle established in Genesis 1:27, with significance for the origin and destiny of human beings as embodied creatures. In this concept, human beings have the freedom to become more or less like God through relationships with God and others and themselves (Pattison 2013, pp. 119-20). Therefore, each person has value and is worthy of inclusion and respect. Bryden, with a lived experience of dementia, reflects as to what it means to her to be truly human and in relationship with God who is love (Bryden 2016, p. 14). In this concept the person has intrinsic significance and worth which can never be lost, even as they live with advanced dementia. According to Christian belief, we are created to be in relationships providing trust, hope and meaning wherein each person is known, infinitely precious and loved (Reinders 2008, p. 252). Eiesland (1994, p. 100), a person living with disability, emphasises that people living with disabilities are the image of God precisely because of their disabilities. Her conception reflects her belief in the God whose relationships are inclusive and interdependent with diverse persons. This is a counter-narrative to that often promulgated in society that perfection is about a person's health, wealth, youth and public worth (Woźnica 2019).

Kitwood and his fellow pioneers advocated for the recognition and preservation of personhood in providing care for people with dementia, particularly in the moderate to advanced stage. Personhood and/or being in the image of God, challenge the concept of one becoming of lesser value when they live with a physical or other condition. They remain a person. Jewish philosopher, Buber emphasises the "I-Thou relationship" (Buber 1966), wherein relationships with another recognise the other person as a being of worth, and each interaction with another as having value (Buber 1957). Moreover, personhood is not just an individual notion, but it exists within cultural and communal situations of value, respect and dignity for people with advanced dementia. Being in the image of God is not an image of individualism and isolation, but is founded in relationships - relationship with God, with one another, and within oneself. Hudson describes a radical ontology grounded in Christian-Jewish theology:

> *The first word and the final word relating God's faithfulness to dementia, … is love. We are not left to search blindly in the hope someone will respond. We have already been found. We are all forgetful of God's everlasting faithfulness; in solidarity with*

> *persons living with dementia, whether we remember or not, we are remembered. We are loved (Hudson 2016, p. 65).*

Hudson emphasises God's faithfulness in loving relationship towards, and solidarity with each person. Christian theology seeks to be both contextual and practical. This solidarity is founded in God's faithfulness to humanity, and grounded in God's relationships of love for all people, which becomes manifest in our relationships with one another (Hudson 2016, p. 50). The recognition of each person's humanity, worth and rights is reiterated as crucial in residential aged care, necessitating the enhancement of quality relational and interactional care (Douglas et al. 2021; Moyle et al. 2015; Stončikaitė 2021). People with moderate to advanced dementia demonstrate an innate sense of how they wish to differentiate themself and preserve their personhood and individuality within the communal setting and in group activities (Nowell & Thornton 2011, p. 404). Therefore in this communal context the person is able to be "an active agent in creating their own world of meaning" in relationship with others (Gardner 2011, p. 104).

The concepts of being in the image of God and/or personhood shift the focus from the disease process to affirming the unique features of each person. This positioning challenges the presumption that the person who no longer has the ability to speak verbally or to put words together coherently no longer has personhood. Rather the person retains their personhood, their identity created in the image of God from their first until their last breath. This means that each person has significance and value, and is acknowledged, affirmed and protected. This positioning has practical implications, encouraging engagement with the person in the social-relational aspects of their daily life. A recognition by others of each person is displayed in care that is appropriated to them, according to their unique history, needs, preferences, choices and expressions in the moment and through each phase of their life (Nowell & Thornton 2011; Wynn & Khayum 2015). Efforts in "supporting people's existing capabilities, while minimizing the harmful consequences of their incapacities", make recognition and respect practical (Higgs & Gilleard 2016, p. 773). This principle applies to the person's voice and their continuing capabilities in communication. Being 'in the image of God' is never lost by the person. Their personhood is preserved and safeguarded by each person's inclusion in interactive and affirming relationships with others (McFadden, S & McFadden 2012, p. 57). These relationships recognise the person's value, enabling a deeper sense of belonging in community (McFadden, S & McFadden 2012; Swinton 2012b). When the qualities of value, respect, dignity and belonging are the lived experience of people with advanced dementia, they respond accordingly and deeply from their sense of worth and connection. Affirming personhood recognises that a person's voice and their quality of life are also affected by their ongoing capabilities in initiating social interactions with others (Milte et al. 2016; O'Connor et al. 2007). Relationships that enhance the person's well-being highlight the value of being part of a community which encourages a sense of inter-dependence.

Interdependence – connecting, belonging and reciprocity in relationship

Bartlett and O'Connor (2007) stipulate that the notion of personhood is individualised, and needs to expand with theories and practical notions of interdependence and citizenship, to comprehend "the complexities of human experience" (pp. 114-5). Some researchers and practitioners (Kontos, P, Miller & Kontos 2017; McFadden, S & McFadden 2012) begin from the theoretical notions of our common humanity and the importance of our inter-dependence. The feminist ethic of care is founded on the reality of each person needing care as a fundamental human need, and our human interdependence "through and via caring relationships with others" (Sevenhuijsen 2003, p. 183). This stance contrasts with the western view of autonomy and achievement through one's intellect, effort, and independence. Interdependent relationships promote the well-being and care of people through a sense of belonging, denoting trust and reciprocity (Watson 2019). Belonging is an important facet of inter-connecting with others, going beyond inclusion, to the forming of close appreciative bonds in a community of relationships (Slape 2019, p. 240; Swinton 2012b). Christian pastoral theologian, Miller-McLemore (1996), gives an evocative metaphor from nature for interdependence:

> *A "living human web" cannot simply be read and interpreted like a document… If knowledge depends upon power, then power must be turned over to the silenced … we must hear voices of the marginali[s]ed from within their own contexts…(pp. 21-2)*

The strength of this web of interconnectivity assumes relationships are fundamental to life, and each person who is marginalised, has a pertinent voice, and must be included within their context. As a pastoral practitioner and a psychologist, McFadden and McFadden (2012), consider that this relational facet of life enables us to build community, wherein we are friends and neighbours rather than strangers or competitors. Active resistance to the harmful effects of negative stereotypes of people with advanced dementia, takes place "through emphasis on connectedness, commonality, and inter-dependency" (Behuniak 2011, p. 70). In sharing with people with advanced dementia, alongside and open, listening and attending to them, we are mutually encouraged and enriched in our experiences of friendship in flourishing communities (McFadden, S & McFadden 2012).

In reflecting on inter-dependence, Sabat (2006) and Louw (2011) both draw on the notion of 'ubuntu' from South African Zulu spirituality. Ubuntu emphasises we are each persons through one another (Sabat 2006). We are not isolated individuals but deeply influence and impact one another in reciprocal relationships. Louw (2011), in quoting philosopher-theologian Gathogo, describes the aim of ubuntu as creating a communal space for "mutual acknowledgement and a creative experience of interconnectedness" (Louw 2011, p. 187). Our interdependence acknowledges that in each person's life, self-giving and receiving the support of others are needed. This applies equally to people with advanced dementia (McFadden, S & McFadden 2012, p. 58), and challenges the negative and narrow perception of the fourth age since living with frailty and limitation occurs across the life-course. Moreover, through appropriate facilitative support, the person with advanced dementia can maintain agency in those facets of their life according to their intact capabilities, for example in expressing their choices of where they will spend their time, and with whom. Grenier, Lloyd and Phillipson (2017) reframe the fourth age as a phase of precarity when frailty and the need for supportive assistive care becomes part of one's lived experience. Affirmative attitudes and responses of others express support of the person with advanced dementia in their continuing worth, dignity and agency (Grenier & Phillipson 2013).

Citizenship – inclusion and contribution in community

The theoretical notion of citizenship expands personhood beyond the care of the individual and local inter-dependent community, "to wider socio-political matters" (Bartlett & O'Connor 2007, p. 114). An ethos of citizenship calls for an equalities-based approach wherein people with advanced dementia have the human right to be participants, in an inclusive, relational community (Bartlett & O'Connor 2007; Birt et al. 2017; Gilmour & Brannelly 2010; Kontos, P et al. 2017).

People with advanced dementia may not be able to realise all their citizen's responsibilities and rights. However, they contribute to relationships in the community of an aged care home through their embodied presence and participation "in reciprocal relationships and care" (Kontos, P, Miller & Kontos 2017, p. 184). Their "relational citizenship" means that others in that community commit to engaging in relationships of respect and valuing the person, and of appreciating their lived experiences (Kontos, P, Miller & Kontos 2017). Enacting citizenship means that these principles are embedded in the ordinary language, routines and activities of communal living (Ward, Campbell & Keady 2016). Such a community values and provides opportunities for the contribution and ongoing capabilities and capacities of its citizens, in the ordinary care of one another in domestic situations which occur each day (Hughes 2011; Shakespeare, Zeilig & Mittler 2017). Sharing in personal care, in meals and other activities together, in supporting their agency and choices, enriches the lives of people with advanced dementia and also those who support them (Brannelly 2016; Kelly & Innes 2013 p. 68). Each person has the right to live each day in these circumstances. Communal living which fosters relationships and communication, continues to provide an environment wherein the person experiences care, safety, acceptance and inclusion, and is able to participate as a citizen (Grenier, Lloyd & Phillipson 2017).

In this sub-section I have endeavoured to present the theoretical notions of personhood and positioning, inter-dependence and citizenship for providing respectful and inclusive perspectives of the person as a framework for praxis in residential aged care. These principles have an underlying ethos of each person having significance and value, belonging and interconnectedness with others, a place and a part to play. In other words, each person has a voice in relationship to others within their context. This notion has the liminal power to perceive people with advanced dementia with renewed vision, as participants and contributors. This is the perspective with which I come to this thesis. This lens arises out of my ontology and approach to epistemology which I describe in Chapter 4.

The Australian Royal Commission into Aged Care Quality and Safety recommends radical reforms that will mean people who are the consumers of aged care services, including all those living in residential aged care, are central participants and contributors to their care. We turn now to the residential aged care context, the setting for the field research of this study.

2.5 Residential Aged Care in Australia

The total number of people with advanced dementia in the Australian population, and the proportion of those living in residential aged care is not clarified in AIHW statistics. However, for many decades now, and currently in Australia when living in one's own home or with family with community support services is no longer an option, many people with advanced dementia live the last phase of their life in residential aged care. The context of residential aged care in Australia will now be surveyed in detail, ranging from an historical overview, wider society's attitudes, its current state, and the findings of the recent Australian Royal Commission into Aged Care Quality and Safety. This section will conclude with consideration of the current statistics of people in residential aged care and the measures implemented therein to enact best practice holistic care.

Due to the lack of community services to support their full-time complex care needs, many people with advanced dementia require residential care. This is considered by many of them as the least preferred option (Royal Commission into Aged Care Quality and Safety 2021a, p. 25). There is a fear and distrust of residential aged care prevalent in the wider community that is also part of the 'stream of the social imaginary' (Gilleard & Higgs 2010, 2017). There may be various reasons for this negative judgement about residential aged care in Australia: its historical and existential reputation, representation by the media, and particularly during the last decade verified cases of abuse portrayed in the media and during the Royal Commission into Aged Care Quality and Safety. I now elaborate on each of these issues.

Historical reputation

Historically, the provision of care experienced by older people was contingent on the prevailing negative societal perspectives towards their maladies. During the industrial revolution across Europe in the late eighteenth and nineteenth century, many older people with confused or volatile behaviour were considered a societal burden, with family unable to manage their care (Andrews 2017). People with dementia and other mental illnesses were incarcerated, certified insane, and committed to lunatic asylums, prisons, workhouses and charitable homes, run by government or charitable organisations, such as the Church (Berchtold & Cotman 1998; Kitwood 1997). Staffed by people with little or no training, in a society with little knowledge about mental illness, people were subjected to "ghastly conditions and treatment" (Andrews 2017; Berchtold & Cotman 1998, p. 177).

Meanwhile, during this period the discipline of psychiatry was developing systematised knowledge of mental illnesses including dementia. There also emerged some humanitarian reformers, including French physician Pinel, who advocated for dementia to be considered as a disease and not a crime. As a result of Pinel and others critiquing the harsh conditions and instigating a regime of inspection of these institutions, some transformed practices began to occur (Berchtold & Cotman 1998). Nevertheless, those living in asylums were still subjected to victimisation and control, with rewards and punishments utilised to modify behaviour (Kitwood 1997, p. 43).The underlying social stigma and stereotyping of people with dementia and contemporary residential aged care, have historical roots that are still residual in society's psyche (Andrews 2017; Gilmour & Brannelly 2010; Higgs & Gilleard 2015).

Perceptions of residential aged care

Contemporary public conceptions of long-term care are part of the stigma and stereotypes attributed to those people receiving such care (Higgs & Gilleard 2021). Residential aged care is often deemed the place that robs a person of their choices, agency, individuality, independence and dignity (Capstick 2017; McParland, Kelly & Innes 2017). The media perpetuate the negative view that family will eventually have to make the decision, "that fills most of us with dread: admitting a parent or loved one to an aged care facility" (Barclay 2014). Anecdotally, residential aged care continues to be described as "God's waiting room", the place where people simply go to die (Tuckett 2007; Walmsley & McCormack 2016). Walmsley and McCormack (2016) conducted a study exploring the career impact for senior health care professionals caring for people with dementia in residential aged care. The study found their work was invalidated by peers, and systemic stigma of residential aged care deemed these places to be 'benevolent asylums' (Walmsley & McCormack 2016).

As well as negative perceptions, entry into residential aged care is also associated with loss and dislocation. Higgs and Gilleard (2015) describe the consequential double grief in leaving one's home and moving into a place of uncertainty and unknowns, provoking a sense of abandonment and anxiety. This transition has been even more traumatic during the Covid-19 pandemic with periods of lock down preventing families and friends from visiting their loved ones, with the resultant effects of social isolation and loneliness (Curelaru et al. 2021). The negative social imaginary coupled with these experiences of grief and loss, social isolation and loneliness, have affected public and personal perceptions of residential aged care. Furthermore, unequal access to best practice care and quality living environments for older people, has perpetuated the tide of discontent surrounding the aged care sector for decades (Andrews 2017).

Australian Royal Commission into Aged Care Quality and Safety 2018-2021

The failures of government aged care services in the state of South Australia, principally at its Older Persons Mental Health Service, led to the claim that "abusive practices are on the rise across nursing homes throughout Australia”. Ultimately this critique led to a media and public outcry (ABC Channel 2 7.30 Report 2016; ABC On-line News 2017; Groves et al. 2017). The Australian Royal Commission was the definitive response of the Commonwealth government to investigate and interrogate the aged care sector and services throughout Australia at every level (Royal Commission into Aged Care Quality and Safety 2021a). The Royal Commission conducted an extensive inquiry, interviewing consumers and interrogating representatives of the stake holders involved in aged service provision. Most significantly, people in residential care or receiving community services, and/or their family representatives, had their voice in making submissions. The Commission report concluded that successive Australian governments, responsible for oversight and accreditation of the aged care system and the service sector, have failed to resolve underlying cultural and practice problems, or provide equal access to quality residential and community care for all older people with advanced conditions (Royal Commission into Aged Care Quality and Safety 2021a, p. 35).

The Final Report determined that the aged care sector has mostly ignored the voices of older people in their needs, choices and preferences, as a result of not valuing them. In her Final Report, Commissioner Briggs determined that:

> *Assumptions about an older person’s cognitive capacity may lead to them being excluded from conversations, staff members talking about them as if they are not there, and their privacy not being respected… Ageism is a systemic problem in the Australian community that must be addressed (Royal Commission into Aged Care Quality and Safety 2021a, p. 76)*.

Briggs highlighted that ageism prevails at micro and macro levels of society, with the harmful effects of disrespecting and marginalising older people, including those with advanced dementia, and limiting social, spiritual, economic and other resources to improve their quality of life.

In addition, pervading the Australian residential aged care sector generally are a broad range of systemic issues leading to “egregious abuse, mistreatment and neglect” (Royal Commission into Aged Care Quality and Safety 2021a, p. 27). One of the major issues relates to the poor resourcing of staffing including: the low level pay structure; high staff turnover; difficulties in recruiting suitable staff; lack of staff training in people’s complex needs; and the inadequate levels of staffing ratios to residents (Australian Health Services Research Institute 2019, p. 29). Referring to research commissioned from the University of Wollongong Commission, Chair Pagone emphasised that

> *[H]alf of Australian aged care residents were living in facilities with unacceptable levels of staffing… Care therefore becomes merely transactional rather than based upon relationships… some of us would see [this care] as inhuman; but it is also inefficient. Knowing those they care for helps care staff to understand how someone*

> *would like to be cared for and what is important to them. It helps staff to care—and to care in a way that reinforces that person's sense of self and maintains their dignity. This type of person-centred care takes time (Royal Commission into Aged Care Quality and Safety 2021b, pp. 8-9)*.

Lack of interaction and care founded on relationships negatively affects the voices of older people living in residential aged care. Inadequate staffing results in the needs of people in their care being unmet with consequential damaging effects on them. In her doctoral thesis into the reconfiguration of personhood in residential aged care, Slape (2019) discerned that many staff seek to provide compassionate and committed care focused on the personhood of residents. Yet these staff often struggle to meet the social and spiritual needs of residents for interaction, relationships, meaning and purpose (Slape 2019). Slape identifies the implications of not responding to the person's fundamental needs:

> *It is their social, emotional or spiritual needs that are being ignored or delayed. Insufficient care such as this is a disregard, or violation, of personhood (Slape 2019, p. 174)*.

Slape is emphatic in her critique, not of staff per se, but of the systemic issues resulting in under-staffing, and their effects on the person living in residential care.

A stipulation of the Royal Commission Report is for radical, determined transformation that protects and promotes the rights of consumers of care, by becoming enshrined in legislation. All aged care services must be "underscored by an approach to care that is grounded in dignity and respect, with an understanding of the experience through the eyes of each older person" (Royal Commission into Aged Care Quality and Safety 2021a, p. 31). The Royal Commission recommends a new aged care agenda founded on dignity and respect of the older person and their lived experience. The basis of this transformative ethos means centring on respecting the personhood and citizenship of older people. This ethos is transformative in responding to their voices as "the consumers of care", "in exercising their rights" with agency, choice and control, and is supported by "advocacy and complaint mechanisms" (Royal Commission into Aged Care Quality and Safety 2021b, p. 14 & 21). This ethos, underlying best practice care, has become the driving force for this thesis. Older people and all associated with the aged care sector await the implementation of the Royal Commission's recommendations and the radical transformation of the sector. Meanwhile residential aged care continues to provide full-time care to many thousands of older people needing these services, with many of the funding and structural pitfalls still impacting the quality of care. As such this sector, in the short term and into the future, needs to fully activate and utilise all available and future measures. The following sub-sections consider the need for excellent praxis and the measures currently available to guide this approach.

Need for excellence in residential aged care

According to AIHW (see Glossary of Abbreviations) statistics, of the total number of people living in permanent residential aged care, 132,000 people, just over half (54%), had a diagnosis of dementia. Four fifths of people with dementia (81%) in residential aged care had an ACFI high care need rating in the cognition and behaviour assessment area (AIHW 2021a, p. 13; 2021c).

These statistics give an insight into the significant numbers of people experiencing moderate to advanced dementia who need and receive full-time residential care. These people have high care needs for ongoing assistance with everyday tasks and health care. The Royal Commission stipulated that, in addition to quality physical care, people require a positive living environment and supportive relationships in order to live well in this significant phase of their life (Royal Commission into Aged Care Quality and Safety 2021a). I argue that each person has the right and need to thrive in a communal home, with quality residential care services, holistic and attentive to their physical, mental, emotional and spiritual characteristics till the end of their life. Internationally there is an increasing plea for research into interventions for people with advanced dementia, to focus on each person living well, with quality of life and well-being (Brown, Mitchell & Quinn 2020; Oudman & Veurink 2014; Oyebode & Parveen 2019).

Measures to promote the person’s voice

Within the Australian residential aged care sector, prompted by changing legislated requirements for accreditation and policy, there has been attention given to the person living well. Policies and procedures are available that support the person according to their individual needs, choices, and preferences. These measures covering various aspects of this phase of the person’s life in residential aged care, are:

- Revised Aged Care Standards Pilot Program
- Palliative Care Approach
- Spiritual Care Guidelines

I now discuss aged care standards as a regulatory measure, a palliative care approach as healthcare, and guidelines for best practice for example in spiritual care.

Revised Aged Care Standards

The Aged Care Quality and Safety Commission is the independent regulator of all Commonwealth funded aged care services overseeing and ensuring their compliance according to best practice, as defined in the Australian Aged Care Act 1997 and the regulatory Aged Care Standards (Aged Care Quality and Safety Commission 2021b, p. 1). The Office of Parliamentary Counsel, responsible for drafting and publishing the laws of the Commonwealth of Australia, confirms the requirements of these standards as the promotion, recognition and support of the person’s voice in the expression of their needs, choices, preferences and what is most important to them (The Office of Parliamentary Counsel 2021, p. 36f). Further to the Royal Commission's recommendations of reforms, in late 2022 the Aged Care Quality and Safety Commission initiated an extensive consultative process with consumers and stake holders regarding the Standards, with further revision anticipated (Aged Care Quality and Safety Commission 2022c). These revised standards will resonate with the Royal Commission's recommendations, emphasising a rights-based and consumer-directed care system. According to the wording of these standards the Aged Care Quality and Safety Commission intends that each person, as the consumer of services, is central. This is to mean that the residential aged care organisation ensures the provision of individualised services tailored according to the person's voice, or their representative's voice, regarding the person's needs, preferences, and choices (Aged Care Quality and Safety Commission 2020). From April 2023 the strengthened Quality Standards are being piloted, (Department of Health and Aged Care 2023) <https://www.health.gov.au/sites/default/files/2023-05/strengthened-aged-care-quality-standards-pilot-program.pdf.> with findings to inform any further changes prior to their formal commencement.

The accreditation of each service provider is contingent on its performance of practices to meet these standards. Where there are poor practices, negligence or abuse, the Aged Care Quality and Safety Commission has substantial powers to warn, sanction, de-fund and close down a residential aged care facility (Aged Care Quality and Safety Commission 2021b). We are yet to see the resultant roll-out of the Revised Standards and how they will be embedded into practices in the aged care sector.

Palliative Care Approach

A palliative care approach to caring for people with advanced dementia is appropriate given the disease's terminal and complex nature (Hughes, Volicer & van der Steen 2018). This approach broadens the biomedical lens, promoting holistic person and relationship-centred care (Broady, Saich & Hinton 2018). An Australian National Palliative Care Strategy was formulated in 2018 based on that of the World Health Assembly. The strategy's principal aim is 'that people affected by life-limiting illnesses get the care they need to live well'. Appropriate person and relationship-centred interventions are put in place early continuing to the end of the person's life (Australian Department of Health 2018, p. 5) <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>. The palliative care approach informs the care of people with advanced dementia and their families, and promotes their quality of life by "correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (Australian Department of Health and Aged Care 2018, p. 4).Therefore the person and their care needs are well-known in a nest of relationships before they become palliative (Broady, Saich & Hinton 2018). However, due to the increased availability of community services, people are coming into aged care homes at a much later stage, for a relatively shorter period (Royal Commission into Aged

Care Quality and Safety 2021d, p. 22). This current situation implies that much intentional holistic care in building relationships and assessing the person’s choices and needs must happen efficiently and effectively.

The evidence available indicates the national strategy of a palliative care approach (Australian Department of Health and Aged Care 2018) is not generalised praxis. Globally it would seem that little attention has been given to researching and providing for the person’s needs holistically (Hughes, Volicer & van der Steen 2018; Murphy et al. 2016). Some studies have discerned the person’s intact capabilities for relationships and communication of their needs and wishes in this phase (Eisenmann et al. 2016; Ellis & Astell 2018; Schmidt et al. 2018). When provided with holistic care within the palliative care approach, the person can continue to live and die affirmatively (Broady, Saich & Hinton 2018; Rumbold 2011).

Spiritual Care Guidelines

The spiritual dimension of the person is recognised as a significant and “integral aspect of quality of life and well-being”, regarding their past and ongoing spiritual needs and choices (Meaningful Ageing Australia 2016, p. 5; Rumbold 2006). The Australian National Spiritual Care Guidelines (Meaningful Ageing Australia 2016) <https://meaningfulageing.org.au/product/national-guidelines-for-spiritual-care-in-aged-care/> were released in 2016, to augment the notion of holistic care in residential aged care. The spiritual facet of care supports and complements the holistic palliative care approach and is mandated in the revised Aged Care Standards (Aged Care Quality and Safety Commission 2021b, p. 71). The Spiritual Care Guidelines provide a framework for best practice spiritual care, giving definitions, core values and principles to ensure their appropriate implementation at all levels of an organisation (Meaningful Ageing Australia 2016).These guidelines offer a range of definitions of spirituality as it is variously expressed by each person. The person experiences meaning and purpose through making connections with those aspects that remain important to them. These aspects may include relationships with others, with some-thing bigger, religious faith or not in God or a higher being, and to themselves, as transcendence of self, engagement with the arts, nature, creativity and places (Fletcher & Meaningful Ageing Australia 2018). According to their spirituality each person transcends self to participate as an intra-connected being, composed of body, emotions, mind and soul, and inter-connected with others, and with the important features of their life, God, or as transcendence (Hudson 2007; Miller-McLemore 1996).

While their spirituality is a recognised feature in many people’s lives, it remains variably understood and provided for in aged care. The National Guidelines are not mandated nor widely implemented (Meaningful Ageing Australia 2016). Anecdotally from recent pastoral experience, meeting the Aged Care Standards means spiritual care is often considered as religious worship and pastoral care provided by external religious personnel to people who are denominational adherents. This approach to spirituality does not provide for the diverse ways the person with advanced dementia may express and enact their spirituality. Spiritual care supports the person in maintaining those deeper connections important to them for meaning, companionship, emotional and mental support, and social interaction. The person may indicate their need to explore and find their unique ‘’ultimate meanings’’ in their final phase of life (MacKinlay 2006, pp. 23-5). These issues indicate the value of having some staff with specialist training in spiritual and emotional care, such as a chaplain or pastoral practitioner, to support people in their various spiritual needs.

Each of these measures or guidelines support the ethos of upholding the person’s unique identity and personhood in their needs, agency, choices and preferences. They acknowledge and provide for the person to express or enact their voice within the communal aged care home, amidst their experiencing personal changes. However, as has been discussed above, each of these measures has their particular challenges with respect to their current recognition, understanding and implementation within the residential aged care context. These factors affect whether and how these measures are implemented, and how the person and their voice are able to participate.

2.6 Conclusion

This chapter has provided the context and rationale for undertaking this thesis. It has identified the global, societal, institutional, relational, and practice-oriented factors that challenge or compromise, or support and enhance the lives of those with advanced dementia and their voices. The increasing number of people with dementia world-wide, supports the need for ongoing diverse approaches in responding to the prevalence of advanced dementia in people’s lives. I posit a nuanced and individualised understanding of and response to people living with advanced dementia, rather than a pre-determined and prescriptive approach.

Tragically, as evidenced in this chapter, ageism is prolific within the wider society and deeply affects attitudes and assumptions regarding older people, including those with advanced dementia, and the delivery of aged care services. Within Australia, as this chapter has described, the system of aged care overall has been found as deeply defective and failing. Within the policies and procedures currently implemented in residential aged care in this country, there is an implicit and explicit commitment to validating the individuality, identity and agency of each person, including those with advanced dementia. However, as identified by the Australian Royal Commission into Aged Care Quality and Safety, current deficits and dysfunction, along with ageism prevalent in the sector and wider society, result in disparate practice knowledge and models of care. Consequently, due weight is not yet given to affirming the personhood of the person with advanced dementia, and holistic person and relationship-centred care. Thereby the person’s voice continues to be impeded, stifled and unheard.

Critiquing the WHO's Global Action Plan, Cahill (2020) comments on its rights-based framework for change which resonates with the reformist recommendations of the Australian Royal Commission into aged care. However, change is also dependent on garnering appropriate transformative policy, legislative and cultural measures within the sector and the wider community, to address the stereotyping and stigmatising of people and their carers living with advanced dementia. As Cahill indicates, visions and policies may remain rhetoric and produce little demonstrable transformation. Those impacted by aged care in Australia wait to see how the Royal Commission's findings will be enacted by government, advocates and service providers. The just positioning of people living with advanced dementia means affirming their personhood, including their voices and recognising their lived experiences as a means of fostering change. This thesis focuses on the person's voice, their strengths, capabilities and capacities, while also acknowledging their increasing frailty. This thesis also embraces the ethos of each person living well, within a residential aged care community which recognises their participation, interdependence and citizenship.

Chapter 3 continues to develop the rationale for this thesis. In presenting a literature review of research over the last decade with regard to the person with advanced dementia and their voice, I further describe the rationale for and approach taken in this research.

CHAPTER 3: THE LITERATURE REVIEW

Introduction

The previous chapter provided a background into the international and mainly Australian societal and local contexts where people with advanced dementia are located, defined and described. This chapter begins by discussing concepts of the person's voice generally, which guided the formation of premisses and an approach to studying the phenomenon of voice. This chapter then moves on to summarise the process of an integrative literature review (Whittemore & Knafl 2005) that was undertaken regarding the voice of the person with advanced dementia. The review identifies the relevant qualitative research in the last decade (2011-2022), from a variety of disciplinary perspectives including the arts, linguistics, nursing, pastoral-spiritual, theology, psychology and sociology. The delineation of particular themes has led to various definitions and descriptions of diverse aspects of the person's voice. Having identified the gaps in the research literature, the rationale for the research questions and objectives for this thesis are outlined.

This chapter is structured in five main sections: 3.1 'Defining the Voice of the Person', considers literature definitions, describes the voice of the person generally and provides an initial working definition; 3.2 'Integrative Literature Review Search Strategy', outlines the iterative process that was undertaken to review the relevant research literature on the voice of the person with advanced dementia; 3.3 'Integrative Literature Review-Thematic Analysis', delineates the manifest and latent themes identified through the review of the remnant research articles, and describes the previous findings of relevant studies; 3.4 'The Voice and Lived Experience of the Person in Research', considers the participation of people with advanced dementia in research and strategies developed to encourage their participation; 3.5 'Conclusion', outlines the gaps in existing knowledge and the rationale for the research questions and objectives for undertaking this study, as my original contribution to knowledge.

The next section considers the phenomenon of voice as it has been variously characterised and described with the objective of developing a working definition for this thesis.

3.1 Defining the Voice of the Person

The broad application of the phenomenon of voice presents challenges to any attempt at definition. The contribution of the work of twentieth century writers who theorise on the person's voice include: German born cultural psychologist living in the United States, Ingrid Josephs (2002); Russian language philosopher, Mikhail Bakhtin (1984, 1987); French-German born, now American, psycholinguist Marie-Cecile Bertau (2007); American feminist-ethicist-psychologist, Carol Gilligan (2003); and Wendy Luttrell and Richard Chalfen (2010), American researchers-sociologists.

Josephs (2002) argues that the voice of the person is important given its significant personal and interpersonal implications as

> *emotionally grounded and personally constructed, and thereby a meaningful focus on a person's life (p. 162).*

Josephs' definition highlights the personal, internal, existential and cultural significance of a person's voice. Resonating with Josephs, Bertau (2008) considers a person's voice as personally constructed, displaying their consciousness in response to lived experiences, both inner and outer. Bertau also describes a person's voice as combining with their outward embodied display. Their voice is therefore a significant and personal manifestation of their identity and agency in their context (Bertau 2007, p. 134). Bakhtin (1987, p. 71) emphasises the dialogical nature of the person's spoken utterance in the interpersonal context, as the means of connecting with others, co-constructing dialogue, and anticipating mutual and meaningful responsiveness (Bakhtin 1987).

Gilligan et al. (2003) describes the person's voice as made up of several different voices in embodied form, combining to signify one's personal footprint. The person's voice continues to be affected and shaped by many factors, historical, existential, social and cultural, impacting the person's "soul" (Gilligan et al. 2003, p. 157 quoting Gilligan 1993). Gilligan's language resonates with definitions of spirituality as that which gives a person's life meaning and purpose (Puchalski et al. 2014). She recognises that with their voice the person is making their unique and embodied connections to who and what is important in their life. This characterisation epitomises the person's voice as a significant pathway to understanding their unique essence as a person. Luttrell and Chalfen (2010) composed an understanding of the voice from the input of field researchers who use participatory visual methodology. The person's voice performs varied and significant purposes including:

> *a capacity for reflection, commentary, perspicacity, creativity and reflexivity about oneself in relation to one's social context. Still the concept of voice spans different terrains, including: 'testimonio' (Lykes) and 'speaking truth to power' (Mizen and Ofosu-Kusi); distinctions between 'personal' and 'group' voice (Lorenz); 're-storying' (Lykes); 'another way of telling' (Radley); and counter narratives (Luttrell)…as a window to who I am…(Luttrell & Chalfen 2010, p. 199).*

I find the argument persuasive that the person, in expressing and/or enacting their voice, may serve a range of unique purposes, such as testifying to and providing a viewpoint into their identity, confronting power, participating in, resisting and providing their perspective as a counter-narrative. While these approaches towards defining the voice vary due to the disciplinary focus of each writer, and emphasise the spoken voice, there appears to be a continuous thread.

These descriptions have suggested a working definition of the voice of the person for this research:

The person's voice is the unique and embodied means by which a person expresses or enacts their lived experience in initiating or responding to diverse internal and/or external stimuli. The person's voice is expressed outwardly in some embodied way, giving their voice social significance and meaning.

This working definition indicates the diverse communicative capacity and capability of people to voice. As such this definition forms the basis for my exploration of the voice of the person with advanced dementia in this thesis.

The voice of a person, or of a specific population has been a particular concern of feminism in confronting and counteracting the abuses of power and oppression of people (Alcoff 1991; Chopp 1992; Gilligan 1982; Gilligan et al. 2003). The notion of voice within a feminist theological critique offers a scope beyond women having their power to voice, and promises

> *emancipatory transformation through the inclusion of multiple strategies, provoking multiple images of human flourishing, and images of difference, otherness, solidarity and transformation (Chopp 1992, p. 18).*

For Chopp, the scope of feminist writers, including theologians, extends beyond the oppression of women to transformation for all people who experience oppression. The negative social imaginary and positioning of people living with dementia generally, and people living with advanced dementia particularly, has social justice implications. As noted in the previous chapters, stigmatising of people living with dementia continues to exclude them through silencing, ignoring and overlooking them as non-persons (Clare, L et al. 2008a; Young, Orange & Lind 2019). This malaise affects the person and limits their capacity to voice themselves in the overall expression of their daily lives. Countering this view is the recognition that no one "gives a person voice" (Ashby 2011). Rather all people inherently have a voice and the right to express their voice and for their perspectives to be acknowledged (Alcoff 1991; Chopp 1992; Lincoln, Lynham & Gruba 2005). Again, Chopp (1992) guides the process of inclusion of voices through "multiple strategies" that do not inculcate power and dominance, but rather "provok[e] multiple images of human flourishing" (p. 18). This approach suggests an appreciative exploration of the voices of people with advanced dementia as a means of recognising and promoting their inclusion and well-being.

This section has considered more broadly the concept of the voice of the person and its significance in their life experience. The next section outlines the process of the integrative literature review and presents its outcomes. This review begins to discern the ways in which definitions and descriptions of the person's voice have been explored with regard to people with advanced dementia.

3.2 Integrative Literature Review- Search Strategy

Search scope

The prime orientation to the data base search was founded in my overall aim to develop a holistic and integrated understanding of the ways the voice of the person with advanced dementia in residential aged care is expressed and enacted. The rationale for undertaking this search was to develop an integrative literature review to identify gaps in existing knowledge on which to base my original contribution. I will now outline the four stage process taken for this integrative literature review (Whittemore & Knafl 2005).

3.2.1 Identifying the problem focus and purpose of the literature review

The purpose of the literature review was to define the specific issue to be explored and to outline the issues pertaining to the phenomenon of the person's voice by considering these questions:

- In what ways are the voices of people with advanced dementia expressed and/or enacted in residential aged care?
- How is their voice promoted?
- What are the gaps in existing knowledge?

3.2.2 Implementing the literature search

As recommended by my supervision team and university research librarian I surveyed a range of electronic data bases with peer-reviewed publications between 2011 and 2022. I chose to limit the search period to this decade when peak organisations have been highlighting the need to include the participation of people with dementia in research (Prince et al. 2016; WHO 2012). The following data bases were used since they compile research citations and articles for the general categories of ageing, social and biological sciences, and the care of older people: Age Line, Cambridge, CINAHL, Informit, Pro-Quest, PubMed, SCOPUS and Social Care On-line. The process also included: a search of Google Scholar to update for current citations; a manual search through reference lists and bibliographies of research articles relevant to this study; and a search through journals not included in these data base searches, particularly journals regarding spirituality and pastoral care. I initially inserted the following key words in the search engines of each data base: "advanced dementia" and "severe dementia" and "residential aged care", "nursing home" and "care home", the latter three being terms used in different countries.

1,088 articles were listed initially. Over 711 articles used terminology in the bio-medical paradigm, and/or were excluded on initial reading of the abstract as irrelevant to the topic or duplicate.

The next words inserted in the search engine were: "voice", "communication", "social", "interaction", "personhood" and "person-centred care", "relationship-centred care", "spiritual" and/or "pastoral care", and "palliative care", "end of life care". 377 potentially relevant articles were listed.

3.2.3 Evaluating the data

These 377 articles were scrutinized according to the inclusion-exclusion criteria in Table 2 below.

319 articles were excluded. 58 articles met all the inclusion criteria.

Table 2 Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Published between 2011 – 2022	Published before 2011
Published in English language	Published in another language
Primary research article	Not primary research article
Peer reviewed journal	Not peer reviewed journal
People with advanced dementia	Not people with advanced dementia
Within residential aged care	Not within residential aged care
Qualitative research article	Quantitative research article
Non-clinical approaches to care	Clinical approaches to care
Person as capable	Person as incapable

The content of these 58 articles was further scrutinized regarding their quality with the Critical Appraisal Qualitative Checklist (CASP-UK 2018). This instrument lists ten criteria by which to assess the quality of a qualitative research article (Figure 1: Critical Appraisal Questions: Qualitative Checklist). This critique was assisted by explanations of the process of critical appraisal of qualitative articles (Chenail 2011; Richardson-Tench et al. 2014).

As a novice researcher I determined that using the CASP Checklist developed by a professional research organisation was a good choice. It provided a careful and thorough checklist yet straight-forward criteria for assessing research articles based on their ethical processes, methods, and decision-making trail. The prioritising of ethical processes and decision making by the researcher are crucial factors in undertaking research (Novek & Wilkinson 2017, 2019; Puurveen et al. 2015). Using the CASP Checklist a further 18 research articles were excluded due to lack of explanation of ethical processes, methods, and/or a decision-making trail.

The remaining 40 articles were deemed of suitable quality for this study (see Appendix 1 Summary of Critical Appraisal of Final Research Articles).

1. Are the aims of the thesis stated clearly?

2. Is the qualitative methodology undertaken appropriate to these aims?

3. Are the design and methods utilized able to meet the aims?

4. Is the sampling strategy, including its size, appropriate to the aims?

5. Are the methods for data generation explained in reasonable detail?

6. Does the researcher discuss their role(s) in the research, and express reflexivity in their practices?

7. Have ethics approval and other ethical issues been given attention?

8. Is the data analysis process outlined, and conducted in a rigorous manner?

9. Are the findings of the research delineated clearly?

10. Is the research useful in its contribution to current literature, recognizing its limitations and suggesting future research?

Figure 1 Critical Appraisal Questions: Qualitative Checklist (Adapted from CASP-UK, 2018)

3.2.4 Analysing the final remnant of articles

The remaining 40 primary research articles were then analysed thematically (see Appendix 2 Summary Literature Review of Final Research Articles). The summary of this data base search for primary research articles appears in Figure 2 below.

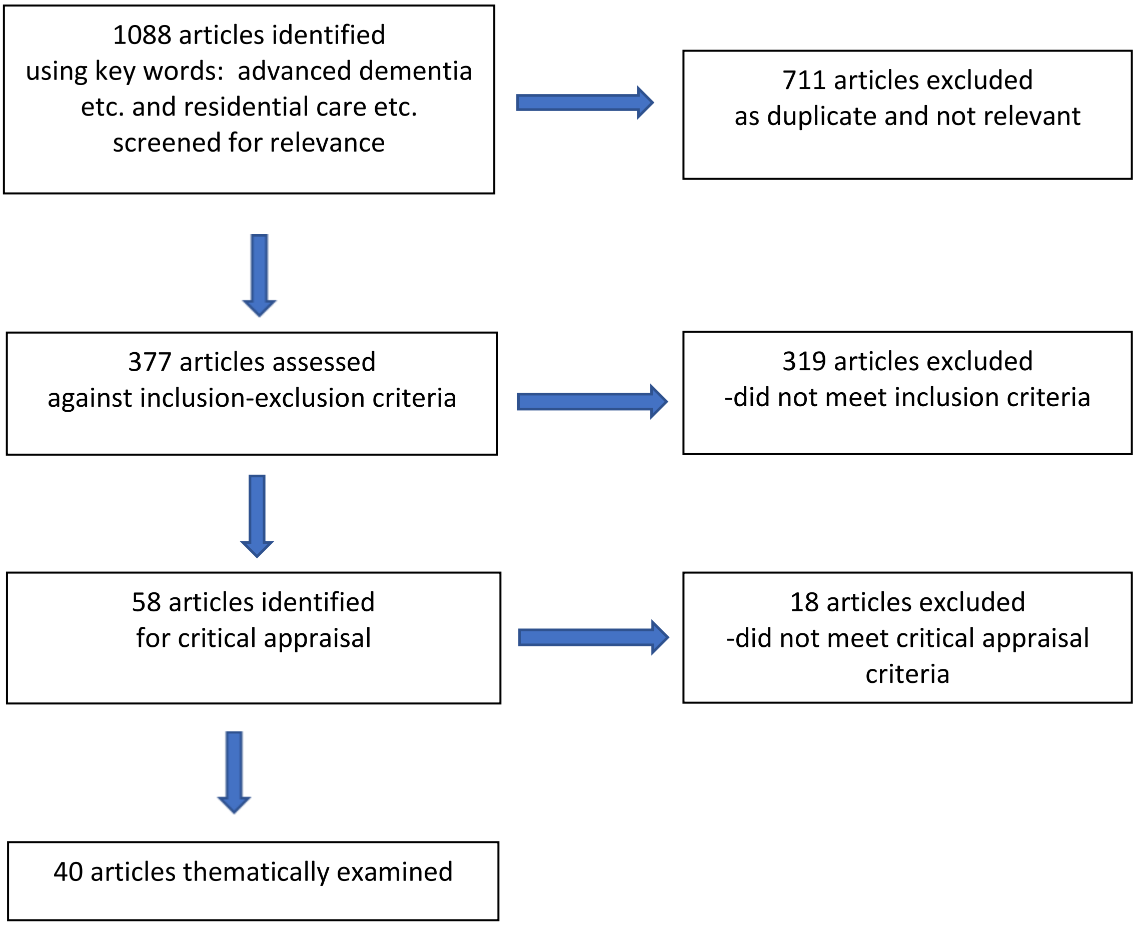

Figure 2 Summary of Data Base Search and Appraisal Process

3.3 Integrative Literature Review: Thematic Analysis

To categorise the 40 primary research articles and gain an understanding of existing knowledge, and also gaps in knowledge, I adapted the thematic analysis process of Marks and Yardley (2011). Each article was first examined according to the aims of its study, by considering the literature review, the gaps in knowledge and development of new knowledge, followed by the methods and the particular findings and themes of the author(s) relevant to the phenomenon of the voice of the person with advanced dementia. Through further re-reading, each article was then allotted a preliminary theme(s), and grouped under these themes. While not adopting the coding system of Marks and Yardley, because I was working on pre-existing research and findings, I found their method useful in determining the diversity of existing theoretical knowledge and the new findings in each article (see Appendix 2 Summary Literature Review of Final Research Articles). Finally, the articles were grouped according to their allocated theme(s) (see Table 3 below: Compilation of themes in research articles). Having undertaken this thematic analysis, the gaps in the existing knowledge were identified. The process of thematic analysis also took account of the latent themes in each research article. That is to mean underlying themes implied in the content, such as the assumptions, attitudes and approaches of the researchers were identified (Joffe 2012).

The next sub-section presents a compilation of the articles grouped around each theme. This is followed by explication of each theme, according to the identified research articles. In the subsequent subsection the latent themes of these articles will be considered.

Compilation of manifest themes

The thematic analysis led to the compilation of the following themes:

1. Voice as representing embodiment
2. Voice as articulating identity, self
3. Voice as testifying agency
4. Voice as storying experience
5. Voice as interacting with others
6. Voice as a being in relationships
7. Voice as expressing spirituality

Table 3 Compilation of Manifest Themes in Research Articles

Manifest Themes	**Research Articles**
Voice as representing embodiment	Bourbonnais & Duchame (2015); Clare, A et al. (2020); Dassa & Amir (2014); Eisenmann et al. (2016); Helleberg & Hauge (2014); Kontos, P (2011); Kontos, P, Miller & Kontos (2017); Nicholls et al. (2013); Peisah, Lawrence & Reutens (2011); Pöllänen & Hirsimäki (2014); Quinn et al. (2014); Shibazaki & Marshall (2017); Walmsley & McCormack (2017); Watson (2016)
Voice as articulating identity or self	Batra et al. (2016); Dassa & Amir (2014); Gjernes & Maseide (2020); Godwin & Poland (2015); Kontos, P (2011); Kontos, P, et al. (2017); Kontos, P, Miller & Kontos (2017); Norberg, Ternestedt & Lundman (2017); Perkins et al. (2015); Quinn et al. (2014)
Voice as testifying agency	Boyle (2014); Cahill & Diaz-Ponce (2011); Gjernes & Maseide (2020); Godwin & Poland (2015); Kontos, P, et al. (2017); Moos (2011); Quinn et al. (2014); Schmidt et al. (2018); Ward, Campbell & Keady (2016); Watson (2019)
Voice as storying experience	Berendonk & Caine (2016); Dassa & Amir (2014); Fels & Astell (2011); Fukui (2011); Hydén (2011a); Kontos, P (2011); Kontos, P, et al. (2017); Palmer (2013); Peisah, Lawrence & Reutens (2011); Pöllänen & Hirsimäki (2014); Vigliotti, Chinchilli

	& George (2019); Watson (2016)
Voice as interacting with others	Boyle (2014); Campo & Chaudhury (2011); Canning, Gaetz, & Blakeborough (2020); Carr, Hicks-Moore & Montgomery (2011); Clare, A et al. (2020); Eggers, Ekman & Norberg (2013); Ellis & Astell (2017); Hydén (2011b); Kontos, P (2011); Mok & Muller (2014); Palmer (2013); Perkins et al. (2015); Saunders et al. (2011); Schmidt et al. (2018); Vigliotti, Chinchilli & George (2019); Walmsley & McCormack (2017); Watson (2019); Wynn & Khayum (2015)
Voice as being in relationships	Allison, Balbino, & Covinsky (2019); Batra et al. (2016); Berendonk & Caine (2016); Canning, Gaetz, & Blakeborough (2020); Eggers, Ekman & Norberg (2013); Eisenmann et al. (2016); Ellis & Astell (2017); Ericsson, Kjellstrom & Hellstrom (2011); Fukui (2011); Hydén (2011b); Nicholls et al. (2013); Norberg, Ternestedt & Lundman (2017); Palmer (2013); Perkins et al. (2015); Saunders et al. (2011); Walmsley & McCormack (2017)
Voice as expressing spirituality	Allison, Balbino, & Covinsky (2019); Carr, Hicks-Moore & Montgomery (2011); Canning, Gaetz, & Blakeborough (2020); Dassa & Amir (2014); Kontos, P, et al. (2017); Moos (2011); Nicholls et al (2013); Peisah, Lawrence & Reutens (2011); Perkins et al. (2015); Pöllänen & Hirsimäki (2014); Saunders et al. (2011); Schmidt et al. (2018)

As indicated in this table a number of the articles contained several themes, implying the close association of the person's various enactments of their voice in their lived experience. Each of the above themes will now be explored in the light of the content of the relevant research articles identified. In addition, reference has been made to earlier research and conceptual literature to further explicate these themes.

3.3.1 Voice as representing embodiment

The research literature has had an ongoing focus on the embodied characteristics of the person with advanced dementia to inform personhood and person-centred care (Kontos, P, Miller & Kontos 2017). Earlier studies had recognised people's intact capabilities and creativity with non-verbal language, visual awareness and social engagement (Clare, L 2010; Sabat 2002). The embodied voice plays a significant role in representing the self and one's history and identity through characteristics such as tone, gestures, and even silence (Sidtis & Kreiman 2011).

Paralinguistic modes that include sounds, laughter, sighing, and screaming are the means by which a person “performs” their narratives, as characteristic of themself (Caddell & Clare 2009; Hydén & Örulv 2009; Kontos, P 2005). The physiological study and treatment of the voice of the older person is a particular focus of the discipline of speech pathology. This thesis will not be considering the pathologies of the person’s voice. Psycholinguist, Bertau (2007) explains the significance of the voice being embodied:

> *Body and voice are inseparable. Voice refers to the body it comes from and the kind of body shapes the quality of voice. Both are social and individual phenomena, manifesting the relationship and tensions between these two interdependent sides (p. 143).*

The person’s embodied gestures express their inner and outer experiences and their awareness of those around them, especially familiar family and staff members (Quinn et al. 2014). For example, a person may close their eyes when another person comes near them, or smile or make a sound in response to their arrival. The philosopher Merleau-Ponty (1962), emphasised that we inhabit and are our body as our presence in the world. The person continues to express their presence and interact with others through their embodied capabilities and capacities into their last phase of life (Kontos, P 2011; Kontos, P et al. 2017; Walmsley & McCormack 2017).

A Canadian study by Bourbonnais and Duchame (2015) discerned that a person may scream to assert their positioning with others, when overlooked or desiring to contribute. The authors recommended that family and staff carers empathise, seek the person’s meaning, and encourage their communicative capabilities (Bourbonnais & Duchame 2015). Such sounds and non-verbal behaviours may be the person’s “reflexive agency”, likened to spontaneity and lying below the person’s cognition, whereby they respond to inner and outer stimuli in embodied language (Kontos, P 2012, p. 3). Capstick (2017) contends that so-called “challenging behaviours” may be the person reacting with embodied agency to precipitating factors, such as feeling intimidated, inhibited or controlled by another person or situation. Based on Bahktin’s work on cultural resistance, the person may be enacting “coping, sense-making and self-determining strategies” in what is a dynamic and communal culture (Capstick 2017). Thus, greater attention is required for a more nuanced interpretation of the non-verbal enactments of a person’s voice. Their embodied language, such as screaming or agitation, may be their voicing of their particular physical issues such as pain (de Witt Jansen et al. 2017; Zwakhalen, van der Steen & Najim 2012). Yet pain often remains unrecognised and untreated, particularly in the person’s palliative care (Brecher & West 2016). The person’s unique physical attributes and non-verbal expressions of their needs and choices are a guide to their individualised care. With careful interpretation of the person’s non-verbal cues and being attuned to their demeanour, staff respond more appropriately with their care, and may enhance the person’s quality of life (Helleberg & Hauge 2014; Watson 2016).

Familiar activities include playing music with others (Clare, A et al. 2020), singing and entertainment (Dassa & Amir 2014; Shibazaki & Marshall 2017), art and craftwork (Peisah, Lawrence & Reutens 2011; Pöllänen & Hirsimäki 2014). These activities facilitate the person's embodied voice and evoke their non-verbal responses of pleasure and calm. Intact embodied abilities and expressions of voice are part of the person's selfhood, residing in one's whole body (Kontos, P 2011; Kontos, P & Martin 2013). Ellis and Astell in the United Kingdom have devoted their extensive research to identifying and facilitating the embodied ways in which people with advanced dementia continue to be able to interact (Ellis & Astell 2004, 2011, 2017). Ellis and Astell (2017) have defined this ability as each person's own "communication repertoire":

> *a unique communication repertoire comprising a variety of nonverbal components, spanning eye gaze, emotion expression, and movement (p.1).*

Embodied language is important for the person with advanced dementia as a way of continuing to enact their inner experience and responsiveness to outer stimuli. Thus, the person articulates aspects of their individuality and identity in embodied form.

3.3.2 Voice as articulating identity or self

The self as one's identity has been recognised as preserved and present in the person with advanced dementia (Batra et al. 2016; Sabat 2002). Yet self is a concept lacking a specific theoretical framework and definition (Caddell & Clare 2011). Voice and self are not synonymous, but rather as entities of human being each has a significance which affects the other, since "[v]oice testifies self exists, and self gives voice a body of content to express" (Yancey & Spooner 1994, p. 302). Self is articulated or enacted by a person's voice. Earlier studies have framed the concept of self as including past and present roles, personality, and narrative memory, as well as one's personal characteristics and feelings in the present (Caddell & Clare 2009, 2011; Hermans 1996). More recent studies have found that people with moderate to advanced dementia express a continued sense of their self in their narratives (Godwin & Poland 2015; Perkins et al. 2015). Batra et al (2016) analysed semi-structured interviews with people with moderate to advanced Alzheimer's type, according to Sabat's (2002) earlier configuration of self. They identified that people with advanced dementia show their continuing sense of self in using personal pronouns "I", "me" "my" and "mine". The person uses these pronouns in describing their intact personal attributes and abilities (Batra et al. 2016; Sabat 2002). The formation of their self-identity, as a life-long process of becoming (Parse 1991), continues as the person expresses their narrative life with others (Batra et al. 2016). Through their intact capabilities and capacities the person continues to express characteristics of their self. For example, for some people part of their identity is their sense of authority, and for others their courtesy or kindness.

A person may express their well-being and historical and cultural identity through familiar activities, such as their traditional music (Dassa & Amir 2014). One’s identity may also be seen in their expressed desire to return to the familiarity, comfort and security of “home”. In one Swedish aged care home, staff identified what elements provide homecoming moments and home-like places and intentionally offered these, bringing comfort and reassurance to the person (Norberg, Ternestedt & Lundman 2017). Continuity theory was coined by Atchley (2003) to explain the ways in which an older person needs to maintain those aspects of life most important to their identity and spiritual well-being. According to continuity theory, the person expresses their essential self as a continuous and consistent thread through their connection with familiar places like “home”, relationships and activities with personal meaning (Atchley 2003). When the aged care setting is home-like with familiar objects, interactions, relationships and routines, the person’s identity and agency in making their choices are encouraged and preserved. The person may then come to call this place their “home” (Gjernes & Maseide 2020; Simpson 2006).

3.3.3 Voice as testifying agency

The person’s agency has been defined as “an ability to take action to exert a degree of control over one’s life” (Killick & Allan 2010, pp. 32, 105). Agency demonstrates a person’s desire and initiative to take action to promote their needs, choices and decisions regarding their life. Connected with this is the notion of autonomy, “the ability to choose what one does” (Killick & Allan 2010, p. 32). In the research literature there is another line of thought relevant to the person’s embodied language. Boyle (2014) uses the term “body language” (p.1137) in her focus on the person’s bodily and facial movements and gestures as expressing their agency. Other studies have pursued this line of thought, finding that the person’s embodied self has an innate capability to be agential, expressive and responsive both creatively and intentionally to signify their meaning (Cahill & Diaz-Ponce 2011; Godwin & Poland 2015; Quinn et al. 2014).

A range of research studies explore the ways in which the person’s embodied language expresses or enacts their agency. Some people with advanced dementia express their agency in their humour, sarcasm, or irony during their interactions with other residents and staff (Moos 2011). These communicative devices enable the person to retain their identity and agency in creative and interactive ways with others (Moos 2011). The person may display their deliberative agency, in self-reflecting, making a decision, and acting on it non-verbally and creatively (Boyle 2014). Therefore, bodily actions such as pushing away a spoon, along with facial expressions, or pushing away another person “should be taken seriously as communicative, interactive, informative and intentional” (Kontos, P 2004, p. 835). Ward, Campbell & Keady (2016) describe some enactments of agency, such as attention to one’s embodied appearance as being active resistance to being and doing the same as others, and seeking to be one’s unique self. People continue to have a need for self-determination through “being me”, and engaging in and affecting their situation in the aged care home (Schmidt et al. 2018). Attentiveness to the person’s “embodied autonomy”, enacted in their gestures and sounds, may guide the crucial end of life decisions by familial and formal carers regarding the person's need for comfort care (Watson 2019, p. 558).

As an aspect of their agency many people continue to critique and inform service delivery in their words and non-verbal enactments (Cahill & Diaz-Ponce 2011). The ongoing agency of the person may be facilitated by carers through a multi-faceted holistic approach to their care through: providing slower relational care (Lillekroken, Hauge & Slettebø 2017); supporting their dignity and interdependence in personal care and activities (Gjernes & Maseide 2020); knowing the person and asking for their choices and preferences (Fetherstonhaugh et al. 2016); and encouraging their sense of self-esteem and confidence (Kontos, P et al. 2017).

The ways in which the person enacts their agency will often be consistent with their storied experience of life, which I will term, their "storied-life", in their various roles and relationships.

3.3.4 Voice as storying experience

In being able to make choices, contribute to, and be responded to by others, the person may enact their story (Berendonk & Caine 2016; Palmer 2013; Perkins et al. 2015). Each person has a story to tell, not just any story but their own story, "a motivated story, which is rooted in emotions", and connects with their memories (Frank 2013; Josephs 2002, p. 162). Sacks (1985) describes the significance of one's story:

> *…for each of us is a biography, a story…a singular narrative which is constructed, continually, unconsciously, by, through and in us-through our perceptions, our feelings, our thoughts and actions…and our spoken narrations…historically, as narratives-we are each of us unique…We must have ourselves…possess our life stories…recollect ourselves…to maintain [our] identity (pp. 105-6).*

Each person's storied-life is unique and intertwined with their identity. Furthermore, research into human embodiment has shown that our story is imprinted on our bodies, pre-cognitively throughout our lives. The person with advanced dementia enacts their story in their unique language, through a word or a phrase, a gesture, facial expression, and/or in ritualized body language (Kontos, P 2011; Kontos, P et al. 2017; Watson 2016). For example, when a person sneezes, they may cover their nose with their hand; when they receive something they may say, "Thankyou"; and when a person is given a drink at the table, they may raise their cup with "cheers".

Storytelling and/or reminiscing of past experiences is a predominant form of narrative for people with advanced dementia, a way for them to perform and affirm their agency, dignity and identity (Hydén 2013). In storytelling the person expresses meaning and experiences well-being (Hydén 2013). A study in the United Kingdom using an intervention of interaction with photographs found that people are still able, according to their communication repertoire, to tell at least one story about themself (Fels & Astell 2011). Again participation in activities that are meaningful and familiar to the person, such as singing, craft or a church service, provide a medium for reminiscing about their past with others (Dassa & Amir 2014; Peisah, Lawrence & Reutens 2011; Pöllänen & Hirsimäki 2014). In America a unique intervention of storytelling, Timeslips ©, was used in weekly small groups of people with varying stages of dementia in an aged care home. Most participants interacted in expressing or enacting at least one story according to their capability, verbally or non-verbally. The intervention was premised on personhood and supporting remaining strengths and capacities, while "creating a meaningful social role" for each participant (Vigliotti, Chinchilli & George 2019, p. 164).

Storytelling by people with advanced dementia does not rely on cognitive coherence and thorough interpretation of the story line (Hydén 2013). Rather it becomes a reciprocal and collaborative experience with the encouragement of family and staff members (Hydén 2011a, 2013). The collaborative listener assists the person's creativity in storytelling through a joint process of building on the story's thread, verbally and non-verbally, with mutual rapport (Hydén 2011a). Being with the person in relationship and encouraging and affirming their story occurs through mirroring their emotions, words, sounds and gestures. Others' responsive actions like a questioning rising inflection display interest and alignment and encourage the person to continue reminiscing (Berendonk & Caine 2016; Davis & MacLagan 2014; Hydén 2011b). "The collaborative", "performative and embodied aspects of storytelling" are a rich resource of interaction with the person (Hydén 2013, p. 360). Thus, storytelling fosters relationships and well-being between people (Berendonk & Caine 2016; Palmer 2013).

In summary, the research literature identifies that the person's voice continues to express their identity, agency and storied-life in their interactions with others (Kontos, P 2011; Kontos, P, Miller & Kontos 2017; Quinn et al. 2014).

3.3.5 Voice as interacting with others

People with advanced dementia often have an ongoing tacit knowledge of interacting with others, using both verbal and non-verbal means (Greenblat 2011; Killick & Allan 2010; Kitwood 1997; Sabat 2003). This capability relies on their characteristic sociability being "an embodied dimension of selfhood" (Kontos, P 2011, p. 341). People with advanced dementia retain the need, motivation and abilities to reach out and engage with others in casual conversations of considerable length. This occurs through preserved communication rituals or habits such as courtesies, greetings, with turn-taking, creativity in word finding, and gestures (Mok & Muller 2014; Perkins et al. 2015; Saunders et al. 2011; Watson 2016). However, at times other residents may not meet the person's need for social interaction through their day (Schmidt et al. 2018). When some interactions do not go well, there must be safe supported egress facilitated by staff (Mok & Muller 2014). On the contrary, a study focusing on a person's making of noises found that other people responded to these sounds as being a part of the interaction (Hydén 2011b). Hydén’s study counters the attitude that a person’s noises may be incidental, irrelevant, or even interruptive and disturbing of others’ peace. When others respond to the person’s “noise making” as a meaningful contribution, this fosters the person’s participation and encourages their reciprocal interaction and pleasure.

An Australian study by Walmsley and McCormack (2017) identified factors that facilitate interaction between the person and their family. The person’s awareness may vary, but they often recognise when their family are attuned to interacting with them. “In-step” interaction means the family member engages with the person by adjusting their interaction to the person’s communication repertoire. Family’s responsiveness makes the time pleasurable (Walmsley & McCormack 2017, p. 626). When family are attentive to their relative’s “needs, desires, moods and concerns” they are supportive of their personhood and abilities to interact (Palmer 2013, p. 224).

The attitudes and approaches of staff in the aged care home are strong determinants of how a person relates to others and their environment (Kitwood 1997, p. 7). When the management and staff are relational and interactive with people, rather than remote or controlling, they continue to promote their personhood (Palmer 2013). Several studies provided a window into only one person’s enactment of their voice in response to another’s attentive listening (Carr, Hicks-Moore & Montgomery 2011; Eggers, Ekman & Norberg 2013). A unique approach to the speech therapist’s role is the “habilitation” model wherein a person’s communication strengths are encouraged in a carefully chosen meaningful activity (Wynn & Khayum 2015). A recent study of a weekly intergenerational dance programme in which people with advanced dementia partnered children, led to the development of trusting interactions and relationships across the generations. This experience gave the children a positive insight into older people’s capabilities and capacities (Canning, Gaetz & Blakeborough 2020).

When staff gather people in informal small interest-focused groups through their day, participants are encouraged to relate to one another meaningfully and enjoyably (Campo & Chaudhury 2011; Vigliotti, Chinchilli & George 2019). Such opportunities prompt each person’s agency in their “body language” of interaction rituals, such as being attentive, turn-taking, mirroring gestures and sounds, and initiating responses (Boyle 2014, p. 1137; Clare, A et al. 2020; Mok & Muller 2014). Places that are light and fitted with comfortable, carefully placed furniture, further enhance interaction, comfort, well-being (Campo & Chaudhury 2011), and build relationships between people.

3.3.6 Voice as being in relationships

Relational approaches to research were not explicitly discussed in many of the 40 studies, but relationship appeared a central component, implicit in the research design and findings. For example, group activities and times together provided people with opportunities to connect, communicate, reminisce, and thereby form relationships with one another and staff (Hydén 2011b;

Norberg, Ternestedt & Lundman 2017; Saunders et al. 2011). The person maintains their dignity, sense of identity and ability to continue to contribute to others through caring relationships that are reciprocal and supportive (Allison, Balbino & Covinsky 2019; Perkins et al. 2015). Positive responses of people with advanced dementia indicate that personal relationships give value, affirmation and joy to their life (Batra et al. 2016). The importance of sustaining ongoing relationships with family for the person's sense of connectedness, meaning and well-being, were the focus of several studies (Palmer 2013; Perkins et al. 2015; Walmsley & McCormack 2017).

Forming relationships with staff also supports residents in their continuing sense of meaning and well-being, through affirming their life story, identity and "narrative agency" (Berendonk & Caine 2016; Ericsson, Kjellstrom & Hellstrom 2011). Conversely, descriptions of the unmet needs of agitated people with advanced dementia reveal a high prevalence of loneliness/need for social contact, boredom/need for meaningful activity, and distress and discomfort (Cohen-Mansfield et al. 2015). A major impediment to relational care is staff being task-focused and feeling time pressured. Thereby staff may not recognise their own lack of interaction and relationship with each person as precipitating the person's distress (Cohen-Mansfield et al. 2015). Moreover, staff often lack specific training in personhood values, communication and developing relationships (Berendonk & Caine 2016; Eggers, Ekman & Norberg 2013). The irony is that attention to the formation of positive and reciprocal relationships has the power to change perceptions and enable people to become more engaged, interactive and relational with one another (Canning, Gaetz & Blakeborough 2020; Walmsley & McCormack 2017). Through relationship-centred care people develop trust that others will spend time with and listen to them, stimulating the person's responsive voice (Allison, Balbino & Covinsky 2019; Canning, Gaetz & Blakeborough 2020). This need behoves the provision of chaplains, life-style and voluntary staff with the specific role of listening and encouraging meaningful interactions. Implementing such approaches as "slow nursing", means being person and moment-focused (Ericsson, Kjellstrom & Hellstrom 2011; Lillekroken, Hauge & Slettebø 2017). Relationships with each person gives nurses an understanding of them, their past, their needs and their ways of communicating (Eggers, Ekman & Norberg 2013).

Becoming an inter-dependent relational community (Allison, Balbino & Covinsky 2019) promotes the voice of the person in this last phase of their life (Eisenmann et al. 2016; Ericsson, Kjellstrom & Hellstrom 2011; Nicholls et al. 2013). The studies of Norberg, Ternestedt & Lundman (2017) and Fukui et al.(2011) responded to the specific need of some people who repeatedly voice their distress and desire to return home. The former study found that relational connectedness through being together in a homely atmosphere, especially in the late afternoon, provides the person with familiar support and companionship to settle and sense being at home. Based on their findings Fukui et al. (2011) developed a model of care of listening to the person's concerns, acknowledging their inner and storied experience of relationships, and discerning the precipitating situated reasons for their need to return home in their key words and actions. Two studies of end-of-life care described how relationships between the person and staff facilitate this care, in responding to the person's non-verbal gestured language and providing companionship, comfort and pleasure in gentle touch (Eisenmann et al. 2016; Nicholls et al. 2013). Ellis and Astell (2018) described using the intervention of Adaptive Interaction to mirror a person's non-verbal language and sounds and develop interaction and relationship with them in the last phase of their life. The person is also able to reciprocate and enjoy extended engagement, by mirroring the communication partner, and initiating their communication repertoire of non-verbal animated body and facial gestures and sounds (Ellis & Astell 2018). Some commentators affirm that for the person with advanced dementia, communicating, interacting, and relating meaningfully with others is "a spiritually significant experience" (Kristjanson 2006, p. 195).

3.3.7 Voice as expressing spirituality

Spiritual care practitioners consider the provision and experience of relationships is expressed within spiritual care (Hudson 2003, 2012; Meaningful Ageing Australia 2016; Rumbold 2006; Swinton 2012a). The National Spiritual Care Guidelines define relationships broadly as being with "family, friends, religious faith community, staff, volunteers, health care professionals and God/ other higher being" and "may also be felt with places, events, times, animals and objects" (Meaningful Ageing Australia 2016, p. 10). This broad ranging description acknowledges the increased importance of relationships in the latter phase of the older person's life, when previous relationships may have been lost with their consequent grief. Other relationships will not take the place of those lost, but provide a nest of relational care and support needed by the person for ongoing strength, meaning and purpose. Two research studies highlighted that people with moderate to advanced dementia, their families, and staff, define spiritual care as continuing those deep connections with aspects in the person's life that are important to them. For many people, this is about connecting with others in meaningful relationships (Carr, Hicks-Moore & Montgomery 2011; Perkins et al. 2015).

Each person's engagement in activities of personal significance to them, facilitates their deeper connections with others and brings meaning to their life in the present (Meaningful Ageing Australia 2016). Some studies exploring the efficacy of particular activities on participants did not term them as "spiritual". Nevertheless, elements of spirituality such as forming deeper connections through engaging in interactions and developing relationships, finding deeper meaning and purpose, participating in activities of importance to the person, and effecting their well-being, were discerned and discussed. Such activities specific to each person are according to their personal interests, history, culture, beliefs and choices and may include: being in nature (Perkins et al. 2015); being in solitude surrounded by familiar possessions (Perkins et al. 2015); engaging with music in various ways (Canning, Gaetz & Blakeborough 2020; Dassa & Amir 2014; Perkins et al. 2015); enjoying humour and laughter (Moos 2011; Perkins et al. 2015); appreciating gentle touch (Hudson 2012;

Nicholls et al. 2013, p. 571); participating in art and craft (Peisah, Lawrence & Reutens 2011; Pöllänen & Hirsimäki 2014); participating in rituals religious or otherwise and relating with God or as transcendence(Schmidt et al. 2018); sharing in relationships; reminiscing one to one and in groups (MacKinlay & Trevitt 2012); and walking (Brannelly & Bartlett 2020).

The various studies listed above described the effects of the person's participation, verbally and /or non-verbally, as their particular expression of their voice. Such involvement connects them with the deeper aspect of themselves, giving them a sense of meaning and purpose, well-being, pleasure and enjoyment. I will return to a discussion of spirituality in the following chapter (Chapter 4) as I develop an appropriate methodology for the research study. Having discussed the manifest themes in the 40 research studies, the next sub-section considers the latent themes identified in these studies, underlying the research designs and analysis of their findings.

Positioning of research literature: recognition of latent themes

Thematic analysis in this literature review also generated latent themes, implicit in the positioning, presumptions and attitudes expressed and implied by the studies' authors (Joffe 2012; Marks & Yardley 2011). The consideration of latent themes is significant since these influence the implementation and analysis of a research study (Wolverson, Clarke & Moniz-Cook 2016). These latent themes are now named and explicated with examples of articles applicable to each theme.

Person and relationship-centredness

The authors of the 40 studies were almost unanimous in positing person and relationship-centred approaches to undertaking their particular project. However, in only a few studies were people with advanced dementia positioned as active and central participants in the research process (Cahill & Diaz-Ponce 2011; Campo & Chaudhury 2011; Carr, Hicks-Moore & Montgomery 2011; Godwin & Poland 2015; Watson 2016). A few researchers described the person as an equal contributor, and interactions with them as being reciprocal (Ericsson, Kjellstrom & Hellstrom 2011; Kontos, P et al. 2017; Nicholls et al. 2013). Various methods enabling the inclusion of people with moderate to advanced dementia, were outlined in several studies (Cahill & Diaz-Ponce 2011; Carr, Hicks-Moore & Montgomery 2011).

Strength-based perspectives

A prevailing assumption of the researchers in the majority of the 40 studies is that the person with advanced dementia has certain ongoing capacities and capabilities, including their unique communicative capability. This assumption was verified through the research experiences, analysis and findings of the particular study. Therefore, the research process of each study demonstrated researcher attitudes and research approaches consistent with a capabilities or strength-based stance (Ericsson, Kjellstrom & Hellstrom 2011; Godwin & Poland 2015; Saleebey 1996; Walmsley & McCormack 2017). The researcher adapted to and emulated the person's language patterns (Eggers, Ekman & Norberg 2013; Ericsson, Kjellstrom & Hellstrom 2011; Walmsley & McCormack 2017). The researchers provided the person with time, not interrupting, diminishing, nor outpacing them (Perkins et al. 2015; Walmsley & McCormack 2017; Williams, K 2011). When the researcher perceived the person as capable of communicating, they reciprocated and reinforced the person’s expressions (Eggers, Ekman & Norberg 2013; Fukui et al. 2011).

The latent themes of person and relationship-centredness and strength-based approach to inquiry were implied in the remnant 40 research articles. Some studies also provided examples of how to undertake research with people with advanced dementia as participants and key informants, as will be discussed in Chapter 4 following. Nevertheless, the following section considers the participation of people with advanced dementia in research to be a contested issue.

3.4 The Voice and Lived Experience of the Person in Research

The 2016 World Alzheimer’s Report recommended the urgent need to explore and incorporate the perspectives of people with dementia to better inform care planning and service delivery (Prince et al. 2016).The WHO has declared that the participation of people with dementia is a global public priority in the research agenda (WHO 2012). This priority embraces person and relationship-centred approaches to care, emphasising that service providers and researchers recognise, understand and respond to the personhood, uniqueness, needs and preferences and the lived experience of individuals living with dementia. The inclusion of people with dementia in all stages acknowledges their need for relationships, and to continue to participate and make their contribution in their situation and setting (Kolanowski & Barksdale 2014; Nolan et al. 2008). This world view shapes the agenda for this thesis, with its particular emphasis on researching with people with advanced dementia.

For several decades further developments in research methods, such as video-reflexive ethnography and participatory action research, have facilitated the contributions of participants (Carroll 2009; Hubbard, Downs & Tester 2003; Koch 2015; Novek & Wilkinson 2017; Puurveen et al. 2015). Researchers have implemented procedures to reduce risk and safeguard the needs and concerns of participants in residential aged care, particularly those with dementia who choose to participate (Luff et al. 2015; Nolan et al. 2002; Novek & Wilkinson 2017; Wilkinson et al. 2015). Ethics approval and its stipulations on the researcher give attention to mitigating the risks. There is a high degree of expectation on the researcher to adhere to the range of ethical protocols regarding vulnerable participants. Development of the necessary protocols for gaining consent has also facilitated the participation of people with advanced dementia (Dewing 2002, 2007). Previously, the informed consent model had dominated and excluded people from participating in the research concerning them. The process consent model affords an alternative systematic, person and relationship-centred approach to undertaking research with people with advanced dementia. The process is just, equitable, and situated. Protocols encompass enabling people to indicate their desire to engage with the researcher, and to be in an assessed state of well-being (Dewing 2002, 2007; Puurveen et al. 2015). This thesis utilises the process consent model with central participants.

Despite these developments in research strategies several systematic reviews have revealed an ongoing exclusion of people with advanced dementia as research participants. Backhouse et al. (2016) conducted a systematic review of twelve data bases for research involving older people as collaborators or advisors in a range of settings in the United Kingdom during the period 1990-2014. Eleven studies were identified. Just one involved people with advanced dementia alone in “ad hoc contact” with the researchers. The authors commented that despite a high proportion of people in residential care “with cognitive impairment and frailty”, they are often precluded from studies or only informally involved (Backhouse et al. 2016 p. 343). A recent Australian scoping study by Hosie et al. (2021) with older people and caregivers did not include people with advanced dementia. Yet that study identified that people with impaired cognition can participate in research “through reducing risks and burdens and increasing benefits for participants”, and also a process of “shared and supported decision-making” (Hosie et al. 2021, p. 7). The scoping review of Phillipson and Hammond (2018) found that no study was exclusively with people with advanced dementia. The reasons given for not including people with advanced dementia as participants were “concerns about communication and memory and …about informed consent” (p. 8).

Research into the psychosocial-spiritual sphere for people with advanced dementia continues to be through the second-hand accounts of others, predominantly with family members (Heggestad, Nortvedt & Slettebø 2015; Quinn et al. 2014), formal caregivers (Cameron et al. 2021), or both groups (Schmidt et al. 2018; Shibazaki & Marshall 2017). There are increasing examples of research into the lived experience of people with dementia in residential care (Alsawy et al. 2020; Moyle et al. 2015). But studies of people with advanced dementia have often used only observational methods of interventions, supported by other evidence such as video footage and researchers’ participant-observation notes of people with advanced dementia and follow-up interviews with those conducting the interventions (Allison, Balbino & Covinsky 2019; Clare, A et al. 2020; Kontos, P et al. 2017; Vigliotti, Chinchilli & George 2019; Watson 2019). Despite the rhetoric of involving people with cognitive challenges in research, there are only a few research studies with people with advanced dementia as central participants, incorporating their lived experiences (Batra et al. 2016; Boyle 2014; Eisenmann et al. 2016; Godwin & Poland 2015; Perkins et al. 2015). Several systematic and scoping reviews have focused on research into the spiritual care needs of people with advanced dementia. These reviews found that the person’s spiritual needs and care are poorly understood by care providers and not integrated into care for people in this stage (Camacho-Montaño et al. 2021). Most studies consider interventions broadly rather than specifically for spiritual care, and have no differentiation of dementia stages (Palmer et al. 2020).

One review was undertaken with the presumption that people with advanced dementia “no longer coherently and intentionally communicate meaning in universally discernible ways” (Kevern 2015, p. 769). This thesis intends to address these gaps in knowledge.

More recently in the United Kingdom innovative approaches to research have ensured that people with lived experience of dementia are included as co-producers in all phases of particular research projects (Williams, V et al. 2020). Thereby those with lived experience contribute their insights and recommendations in collaborative planning, implementation and then in analysis The study’s authors recommend that in the future this model of participatory research could well be expanded to include people with advanced dementia. This thesis assumes the deliberate positioning of people with advanced dementia as central contributors in the research. Their voices express or enact their lived experience. They identify how the communicative responses of others promote and/or inhibit their voices (Luttrell & Chalfen 2010, p. 199). Through this research process understandings of the person with advanced dementia are formed by opening oneself in respectful relationship to the person and their lived experience. Taking into account the context and culture, we are enabled to ask how “any person, experience or event”, may be perceived in different and transformed ways (Gardner 2011, p. 103). Kontos (2006) states that the contribution of people with dementia and their lived experience in research

> *chang[es] our view of the person with dementia from an object of study to a subject whose perspective can enrich our understanding of the complexity of Alzheimer’s [and] will encourage researchers to include explorations of the [person’s] lived experience…(p.119)*

Engagement with people with advanced dementia means their voices are heard, noticed and responded to. Such interactive relationships challenge negative social constructs and positioning, so that stereotypes can be transformed. In her overview of previous studies, Milne (2011) identified several studies prior to 2010 in which people with advanced dementia provided their lived experiences in responding to questions regarding their quality of life. Milne also acknowledged the more recent emergence of narrative approaches to research with people with advanced dementia. People with advanced dementia can contribute to conversation, interaction and research (Milte et al. 2016; Sabat 2003). Research that includes the participation of people with advanced dementia endeavours to appreciate their perceptions about what matters in their lives and promotes their well-being and quality care (Milte et al. 2016; Nolan et al. 2002; Novek & Wilkinson 2017; Puurveen et al. 2015). Importantly, their participation can enhance their sense of worth, relationships and self-expression, for example in their critique of their context (Milte et al. 2016). This thesis presumes this perspective in undertaking research with people with advanced dementia as central participants.

3.5 Conclusion

Thus far I have argued for the voice of the person with advanced dementia to be recognised. It is apparent that their voice is often muted or considered to be non-existent. As discussed in this literature review with respect to the person with advanced dementia, there is a strong body of research literature over several decades that supports their personhood, continuing voice and communicative capability and capacity. The emphasis of these researchers is that people with advanced dementia continue to have daily life in the present and in a future yet to be lived. Moreover, they retain their voice, expressive of their continuing sense of meaning, identity, individuality, and agency (Sabat et al. 2011). I have assumed this perspective as the foundational epistemology for this thesis.

For more than two decades there has been a call for research from within the qualitative paradigm with people with dementia, and specifically with people with advanced dementia, rather than about them (Hubbard, Downs & Tester 2003; Milne 2011; Nolan et al. 2002). Yet there has continued to be limited response to an inter-subjective approach in research praxis (Phillipson and Hammond 2018). The counter-narrative is that including people's lived experiences gives understanding of what matters to the person living with advanced dementia. Their inclusion reflects an actual commitment to the ethos that personhood, person and relationship-centred care are fundamental to their lives.

This thesis responds to the gaps in knowledge that have been identified through the integrative literature review as follows:

- There is a dearth of research positioning people with advanced dementia as central participants, in contributing their responses and perspectives in order to understand their lived experience. In contrast this thesis positions people with advanced dementia as central participants, articulating their lived experience through their enactments of their voice through their day.
- When people with advanced dementia have been included, research has been largely on specific topics, such as their awareness, or eliciting their responses to certain questions. This thesis delves into how and why the person expresses themselves. In addition, this thesis seeks to discern the meaning, significance and interconnections for the person in expressing and/or enacting their voice across their daily life.
- There have been many studies that focus on the roles that family, nurses and carers play in the person's daily life. However, there have been few studies identified regarding the support that family and the staff team provide to the person in prompting and promoting their voice through their day. This thesis includes the participation and perspectives of family and staff members in a range of roles, regarding how they interact with and encourage the person's voice.

- One of the objectives of this thesis is to reflect on how the person’s voice relates to their spiritual dimension and their spiritual care. The integrative literature review has clearly identified a gap in the current research literature into how the voice of the person may relate to their spirituality. This issue has been further explored in the analysis and discussion phases of this thesis (Chapters 8 and 9).

In responding to the gaps in previous research regarding the voice of the person with advanced dementia the objectives of this study are:

- positioning people with advanced dementia as central participants and contributors;
- exploring their lived experiences in voicing themselves, and the significance this has for them;
- examining how the facilitation of family and staff members in a wide range of roles promotes their voices;
- exploring how the person’s voice relates to their spiritual dimension, and how spiritual care praxis may promote their voice.

Chapter 4 explains the underlying ontology and epistemology that led to the qualitative research methodology. Situated in the daily lives of people with advanced dementia, this study required a methodology encompassing empathic and ethical relationship with each person and the commitment to representing their voices.

CHAPTER 4 DEVELOPING THE METHODOLOGY

Introduction

This chapter outlines the foundations of the methodology for this thesis, building on those concepts of the positive social imaginary identified in Chapter 2, namely personhood, interdependence, and citizenship. The preceding chapters engaged critically with different social perspectives by addressing research studies contextually and from a variety of disciplines that included social sciences, speech pathology, medical sciences and Christian theology. I have argued that various contextual and research literatures have provided perceptions of the person with advanced dementia and their voice. However, this literature has rarely included the participation of people with advanced dementia and their lived experience. Their voices have often been overlooked or muted, indicating the importance of undertaking a research study that includes both voice and perspective. This research study therefore focuses on the inclusion, participation, expressions and enactments of people with advanced dementia as the central participants. As a finely tuned endeavour researching with, rather than about, people with advanced dementia, it was important to develop appropriate ethics and a detailed methodological rationale and design (Brooker 2008; Milne 2011). The elaboration of the details of this ethical positioning and methodology occurs in this and the following chapter (Chapter 5).

The three sections of this chapter detail my background and the rationale behind the chosen methodology. 4.1 ‘Positioning the Researcher and the Participants’, narrates my ontological and epistemological positioning of self and the participants. The foundational principles and ethical stance that form and shape this thesis are also explained. 4.2 ‘Defining the Voice of the Person’, introduces a discussion of the phenomenon of voice in the literature and develops a working definition of voice for this study. 4.3 ‘Research Approach’, provides a background to defining and describing the choice of a qualitative approach and the ethnography for the research.

4.1 Positioning the Researcher and the Participants

The significance of one’s world view is founded in the biography of one’s identity. The formation of identity is an ongoing process that draws on a narrative consisting of relationships, beliefs, texts, interactions and experiences (Coffey 1999). In the process of undertaking this thesis, my ontological and epistemological positioning have shaped my values and methodological praxis (Carter & Little 2010). I recognise my ontology, epistemology, and positionality have created a unique pathway into this research and its thesis, affecting my relationships with participants and guiding my interpretations.

Ontology and epistemology

This thesis is grounded in my ontology. Ontology addresses what it is to be human and how meanings are created for a person. This includes what exists outside, around, and beyond a person that enables us to understand "what is said to exist, the meaning of being and beings, and how these might be characterised" (Parker 2015). I am grounded in my Christian faith in God, revealed primarily in the lived experience of the God-man Jesus Christ, and through relationship with Him. My ontology informs my life, my values and ethics, and my daily experience personally. It also informs my pastoral understandings, and now my research praxis.

My faith understandings are explored and mediated through the various narrative genres in the Christian Scriptures. These scriptures provide an understanding of the essence and characteristics of human identity, specifically my identity and how I perceive the identities of other human beings (Louw 2011, p. 174). My Christian faith brings in part an awareness of God's love, regard and concern for each person as created in the image of God. Therefore, each person is of value and worthy of respect (Pattison 2013, pp. 119-20; Woźnica 2019). Christian faith, as narrated in the biblical Gospel accounts of Jesus, is premised on God embracing and welcoming those who struggle and who live on the margins, excluded by others (Byrne 2002; Ringma 2008). This positioning was exemplified in Jesus' life and is to be lived out in the lives of those who choose to follow his way (Chopp 1992; McFadden, S & McFadden 2012; Schussler Fiorenza 1983). Jesus' positive positioning towards people, particularly those whom others overlook, diminish or disregard, has formed my ontological stance. Following the way of Jesus has directed my primary orientation towards developing relationships with people who may be inhibited or prohibited from expressing their voices. This has necessitated, my standing alongside them and being attentive and responsive to their voices. Byrne (2002, p. 52) sums up Jesus' mission to embrace and welcome people, as portrayed in the Gospel of Luke, "as the good news of acceptance, the invitation to all to come and be drawn into the hospitality of God". Each person has the desire and right by virtue of their presence in the world to affirmation with value, dignity and respect, meaning that their voice is recognised and responded to by others. This shapes the lens through which I view the world.

How people are included or excluded by myself and others and how such responses are shaped by societal mores, is an ongoing study that informs my approach to epistemology. Epistemology is defined as "the theory behind knowledge", that is, how we know what we know (Parker 2015). Accordingly, claims are made about how knowledge and knowing, including beliefs, presumptions and assumptions, are formed and sustained (Carter & Little 2010). I am aware that epistemology, arising out of my ontology, constitutes a value base that influences the ways in which my creation of knowledge occurs (Carter & Little 2010). In this research context my ontology and my approach to epistemology provides the interpretive lens for the relationships between myself as researcher and participants. This interpretive lens will guide how participant voices are heard and observed, and how participants are represented.

In summary, my empathic relational approach to this thesis, my methodology and my interpretations are undergirded, orientated and guided by my particular Christian ontology and epistemology. My ontology is that each person has an intrinsic need and desire for relationship and life through being recognised and valued by others, and voicing themself. But that personhood is also dependent on social imaginary and positioning which are socially constructed and maintained. My consequent epistemology is that knowledge of another person is achieved holistically and empathetically by a process of reflexive engagement through developing relationship in an appreciative and strengths-based framework. I will now expand on my background of personal and professional experiences that have shaped my ethos and led to my undertaking this thesis.

Personal and professional experiences

My experiences of engaging with all people and situations within the residential aged care context have been deeply affected by "personal history, biography, gender, social class, race and ethnicity" -all aspects that formed and shaped my ontology and epistemology (Denzin & Lincoln 2018, p. 12).

My experiences of residential aged care have been life-long. Earliest memories are of visiting the aged care home where my mother was an enrolled nurse, to take her home after work. As I waited I spent intentional time with residents because as migrants, we had sadly left our grandmother in England. Relationships with older people have remained an important part of my life. In the 1970s as a social work student, when no training was required, I spent my vacation as a carer in the same aged care home. Talking with older people was one of the most rewarding aspects of this period. I observed some staff relating positively with people, and yet constantly negative practices were conducted silently with little interaction, with some routines quite disrespectful of people's dignity. Subsequently as a student minister, I regularly visited aged care homes, and often found people sitting silently, or confined to bed with staff rarely interacting with them. Instead of interaction, I saw people being talked over or ignored as staff performed tasks on them. In fact, many older people I encountered were, each in their own way, ready to interact with others or myself as we sat together. This was before Kitwood (1987) began to publicly critique practices enacting a "malignant social psychology", advocating for alternative theories of dementia recognising the personhood of people with dementia and implementation of positive care practices.

As a social worker in the mid-1980s, I was part of a pioneering regional aged care assessment team in a rural setting in South Australia. The team visited the person and their family to assess their needs and desires for their care. This work opened new avenues for hearing and responding to the voices of older people. However, those early days of change were challenging. The team negotiated and advocated for the person's wishes to be considered in an environment of limited services. We experienced conflict with other health professionals, used to making diagnostic decisions with little input from the person whose voice remained silent and desires unheard.

In the early 1990s after completing a theological degree and training for ministry, I was ordained and became involved in community and hospital pastoral ministries. These vocations have meant using the skills and knowledge developed through my diverse academic and practical background. Of particular relevance I have often been alongside people with advancing dementia as they transitioned into community services and then into residential care, and through to their final phase of life. For several decades now my pastoral role has involved journeying with older people in residential aged care in meaningful relationships, recognising each person's individuality, listening to them voicing their stories, concerns, needs and desires. Gaining an appreciation and holistic understanding of each person and facilitating their spiritual-pastoral care, has been a reward of this pastoral experience. However, my overall history of professional and personal experiences has revealed residential aged care practices to be disparate in quality and relational engagement, and in some places dysfunctional. I have encountered situations where residents have not been given adequate time to express their practical needs and concerns and to be appropriately responded to. I have observed even less attention being given to their needs for companionship and relationship and to providing opportunities to interact with others.

I have personally cared for my parents with advanced dementia. As a chaplain, I have cared for people with advanced dementia for more than twenty-five years. I have valued our relationships and learnt much as they have shared their life experiences. I have also had the good fortune of continuing to be involved in and work alongside diverse multi-disciplinary teams, which included a range of religious and non-religious spiritual care practitioners and chaplains. Through these opportunities I have appreciated the breadth of knowledge and understanding, and the intuitive, responsive and relational care provided by many staff. I also experience an ongoing sense of a deeper conflict in our society. This is about what it means for a person with advanced dementia to live and have a voice, and yet continue to be perceived as unable to communicate or participate with others. Insights from my experiences have informed my continuing study and my current candidature. My background has influenced the approach, narrative form and foci of this thesis. In embarking on this journey into the daily lives of people with advanced dementia, I have sought fresh awareness, reflexive responsiveness, and new understandings. Continuous reflection on my experiences of relationships with people with advanced dementia has developed an appreciation of, and the desire to study more deeply, their lived experiences, and to reflect more effectively on my spiritual care praxis. My experience has indicated to me that the person with advanced dementia expresses and/or enacts their voice and I wish to contribute new knowledge in this field.

Reflection forms an important aspect of this study. Reflection, like voice, needs to be defined and described as to how this term is used in its various iterations in this thesis. Reflection is premised in my theological contemplations and assumptions, in my process of ethical decision making, and in my analysis of the various extracts and inputs of research participants. I now offer a contextual, working definition and discussion of the use of the terms reflection and reflexivity to show the divergent ways these terms are used in this thesis.

Theological reflection and ethical reflexivity

This project is framed and informed in a specifically Christian way. I consider my Christian theology to be embedded in the text, in its foundations, presumptions, approach to care and compassion in research, its findings and conclusions. I have a personal Christian faith and participate in a community of faith.

In my professional career I am accustomed to working in a range of multi-faith and no faith and multi-disciplinary contexts. As a result I am able to communicate my own Christian beliefs and values respectfully and as appropriate, and hear those of others. My training in various disciplines and diverse roles as a chaplain, pastoral minister and social worker, has developed my eclectic approach to studying a particular topic. I have come to see myself as a bricoleur, a quilt maker identifying and gathering various materials to piece together a many faceted quilt (Herman 1997) and form “a set of beliefs and feelings about the world” (Denzin & Lincoln 2018, p. 19). The French anthropologist-ethnologist, Claude Lévi-Strauss, originally applied the French terms bricolage and bricoleur in his writings concerning anthropological research practices (Levi-Strauss 1966). My pastoral and now research praxis recognise that a single method, academic discipline, or way of gaining knowledge cannot take account of the vast diversity and complexity of human experiences (Kincheloe 2001). Therefore, as a research bricoleur seeking to understand and interpret the voices of people with advanced dementia, I have gathered and adapted various methods and notions for the purposes of this research (Levi-Strauss 1966, p. 18). As discussed in Chapter 2 , a bricolage of theoretical and theological notions has guided this research praxis, and will be added to in this section and chapter (Kincheloe, McLaren & Steinber 2011). The research process has included the formulation of a bricolage of strategies for gathering, analysing and interpreting the various data as will be defined and described in Chapter 5 (Herman 1997). This approach has been modified by my theological reflection and ethical reflexivity as to how I explore, act in, and study the lived experiences of people with advanced dementia***.***

Theological reflection

To wisely respond to the changing circumstances of this era and people’s diverse needs and beliefs, those who provide pastoral care ministries in faith-based agencies within the aged care sector need to be well-equipped. Engagement in ongoing formation and transformation through theological reflection and supervision with a spiritual director are ongoing requirements of my chaplaincy. Both facets are helpful ways to enhance one’s ministry in practising the presence of God personally, and developing pastoral insights through collaborative conversations with one’s colleagues.

Paver (1996) describes the purpose of theological reflection:

> *as a method for integration, with [it's] primary focus on what happens at the intersection of what one believes and how one lives out that belief [within] the movement of the spirit of God in human experience. At these intersections pastoral supervision is concerned about the congruity between belief and practice (p. 94).*

By engaging in this process of theological reflection in this research study, I have sought to understand and interpret the experiences of people with advanced dementia living in residential aged care. Experiences encapsulate both the monumental occasions of transitions, crises, losses, griefs, celebrations and joys, as well as the ordinary everyday ones. These circumstances are the places where I understand God is present and active.

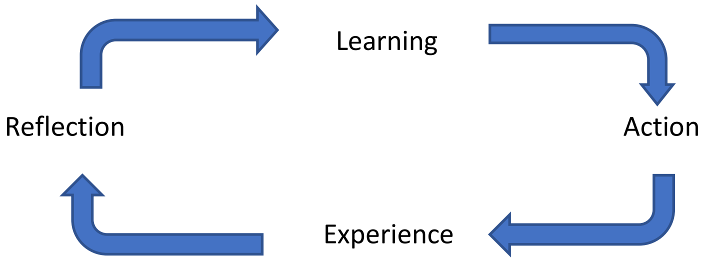

Figure 3 Action - Reflection Cycle of Theological Reflection (Cameron et al 2010, p.50)

For me, theological reflection initially considers an experience and contemplates its many facets in discerning a focus and content of the reflection. Laying aside interpretations and conclusions and being open to listening carefully to others provides the place for experience and further reflection. This may be the place where the wisdom of the sacred texts and traditions and history, as well as common sense and practical experience may speak into this experience being considered. My theological beliefs necessitate my continuing formation proceeding "through participation in and reflection upon this religious faith" (Macquarrie 1977, p. 1). Moving to translating contemplative reflections into action, even transformation within myself and in community, becomes possible with renewed contemplation and consideration, interpretation and understanding. I bring this understanding of theological reflection to the process of analysis within this thesis.

Engaging in theological reflection on experiences, along with continuing inter-disciplinary scholarship in both theology and the social sciences, guide me in my theological reflection. This process has formed my values and ethics with respect to the person with advanced dementia. In Chapter 2 I considered a bricolage of particular theories and their parallels in Christian theology: personhood with image of God; interdependence with connecting, belonging and reciprocity in relationships; citizenship with inclusion and contribution in community. To this bricolage I further add these notions of paradox, human becoming, and narrative form of experience.

Paradox

The notion of paradox provides a lens for viewing the person with advanced dementia. As discussed in Chapter 2, the social construction of people with advanced dementia might be more helpfully understood with a nuanced discussion (McParland, Kelly & Innes 2017). As human beings live longer, this means accepting the accompanying realities of increasingly limited bodies, along with diminishing capacities and capabilities (Brabazon 2018; McParland, Kelly & Innes 2017; Morell 2003). In excavating the notion of paradox, two apparent opposites exist; vulnerability in strength and capability in weakness may be held together as the lived reality of people with advanced dementia (Rohr 2018b). Paradoxically when one confronts one's own vulnerability and weakness, and empties oneself of power and strength, the gifts of strength in grace are mutually given and received (Paver 2006, pp. 76-7).

This thesis assumes an understanding of the realities of ageing as paradoxical, the both/and rather than the either/or (Morell 2003). I argue that weakness and strength co-exist so that the person's experience may not only be about diminishment, deficit and decline but also capability and capacity. This paradoxical perspective has provided a counter-point when describing experience not in terms of dichotomies of either/or, but rather as both/and (Rohr 2018b, p. 235). This allows for the balancing of seeming opposites occurring together as part of the ageing human experience, particularly for people experiencing advanced dementia. Swinton (2012a) reminds us to recognise our interdependence in this and every phase of life, as:

> *"…through the body of Christ…human beings find reconciliation and redemption. It is through the body that the gospel is proclaimed, prisoners are visited, the sick are consoled, lovers love, and righteousness is seen to be done (p. 177).*

The body of Christ, the Church, is but one place where interdependence in relationship and mutual support and encouragement may be practised, as depicted by Swinton. As I have suggested previously, these benefits may be experienced in an aged care home. Both strengths and weaknesses are experienced by each person and we may be present to support one another in relationships. Caring practices need to recognise a person's capabilities and possibilities while considering their limitations and vulnerabilities (McFadden, SH 2004; McParland, Kelly & Innes 2017). We may then envisage and experience "celebrating ageing as a vital part of life" (Baars & Phillipson 2013, p. 26).

Human becoming

In this thesis the notion of human becoming has enabled a deeper appreciation of the movement towards well-being. Human becoming happens in interactions and activities where people's voices are included and respected and they are enlivened. Within the context of open, accepting and empathic relationships, the person may become interactive and/or more relaxed, cheerful and communicative (de la Perrelle et al. 2022; Hudson 2012, 2016). Human becoming may be depicted evocatively as “the dynamic unfolding of Being” (Collier 2013, p. 69). This is to mean the ongoing, continuous, always present and everyday occurrence of the breath of life, not usually consciously perceived, and yet often experienced in interconnected relationships. Parse (1991) applies the paradigm of “human becoming” within the context of nursing and research practices. She defines human becoming as the lived experience of being human, situated in a multiplicity of interactions with oneself, other human beings, other creatures, the environment, and/or the transcendent. Human becoming is:

> *making meaning together through affirming and valuing, co-creating with others in the ebb and flow of relationships, and co-transcending being transformed and transforming the context (Parse 1991, p. 35).*

This description further elaborates on the possibilities of mutuality and interdependence through relationships for the enrichment of daily life. Through connecting meaningfully with others a person and context may transform to be all they are intrinsically and are meant to be (Rohr 2018a, pp. 184-5). Human becoming is encouraged where personhood is affirmed within the ethos of mutual respect, inclusion, and belonging of each person in their uniqueness (Goodall 2014, p. 258). The Christian Scriptures present Jesus as one who offers human becoming for those he encounters and companions along the way, that people might be enlivened and experience life in its abundance (John 10:10). Encounters with others, leading to connection and companionship in relationships, are opportunities for the person to experience well-being and express and/or enact their voice, sometimes responding in narrative form.

Narrative form of storied-life

A description of this research as an exploration of the unfolding of the person’s lived experience through their day highlights its narrative form. Narrative is “a mode of communication” within and between persons (Czarniawska 2004, p. 10), and is a valuable source of knowledge within community and the spiritual dimension of ageing (Swinton & Mowat 2006).

Narratives can influence, impact and change lives. The Hebrew Bible, Gospel accounts of Jesus and then Epistle accounts of the Christian Community, feature many stories of human experiences, endeavours, failure and travesties, interwoven with deeper meanings and truths. The narrative of Jesus’ storied-life continues to be a counter-narrative (Swinton 2012a, pp. 24-5) about what brings help, healing and hope to people’s lives. Often, when a person encounters another’s respect, recognition and responsiveness in relationship they become and are transformed. Narratives co-constructed with another person are ‘meaning making’ activities as the person articulates their storied-life that continues into the present (Riessman 2002). The notion of narrative form as “performance” within a social context (Squire, Andrews & Tamboukou 2013, pp. 8-9), suggests that the person with their intentional or “pre-reflexive agency” (Kontos, P 2012, p. 3) performs their narrative before others. Through their narrative expressions in interactions the person indicates their responses to their experiences and their meanings, and thus their current state of being (Cortazzi 2001; Milne 2011). This thesis presumes this understanding of the person’s daily life playing out as a narrative in which they perform along with others.

In this thesis the term ‘narrative’ embraces a range of forms: social interactions and monologues that contain storied episodes, often of past events (Chase 2018; Hydén & Örulv 2010); combinations of words, gestures, and experiences that form a narrative of interactions (Hydén 2013); and narratives traced across the transcriptions of a number of episodes (Riessman 2008, pp. 65, 135-6). The extracts used for data analysis in Chapters 6 to 8 represent narratives of people’s storied-lives that they have told, performed and reminisced about themselves, their lived experience, and what continues to matter to them. Each person has expressed and/or enacted their narratives in the context of another’s attentive and respectful recognition and responsiveness in relationship. As such the person’s narrative may provide a counter-story of what living with advanced dementia for the person becomes in an interactional and relational context.

The notions of paradox, human becoming, and the narrative form of people’s storied-lives have guided the research praxis of this study. They have provided an interactive and interpretive lens for time spent with each person and groups of people through the fieldwork journey. In the analysis and discussion phase these paradigms became sensitising notions informing the interpretivist stance of this thesis.

Ethical reflexivity

My ethical approach is grounded in the ontology and epistemology of theological reflection on practice, using Christian scriptures and tradition to guide my continuing professional development (Graham, Walton & Ward 2007). This allows my practices to become praxis as defined by Louw:

> *“Praxis” is not merely “practice”. Practice refers to the practicalities such as skill, technique, strategy, projects and the...question of how. With “praxis” is meant: the intention of actions as related to meaning and destiny. It refers to intentionality: the question regarding significance/telos and truth/aletheia). Praxis refers to a practice-based reflection on the intentionality of human actions and the paradigmatic back-ground that determines habitus [practical wisdom] (Louw 2011, p. 173).*

These foundational principles, enacted in my pastoral care, have therefore influenced my research, enabling careful deliberation of choices and decisions in planning and design, implementation, interactions with people, and interpretive phases. Such reflexivity may be defined as thoughtful, conscious self-awareness throughout the research fieldwork. This process allows continual evaluation of subjective responses as ethical, intersubjective dynamics, and enriches the research analysis (Finlay 2002). The principle of self-reflexivity enacting wisdom facilitated “meaningful decision-making revealing responsible doing and significant meaning making” with participants (Louw 2011, p. 174). I recognise that full objectivity is not possible given that human to human communication is subjective. My understanding is according to my background, positioning and perspectives in the arena of this research process (Koch & Harrington 1998). In assembling my methodology, theological reflection has provided sensitising concepts within the context of relationships. My ethical reflexivity has meant being intentional about integrating practices to become research praxis.

Ethical reflexivity and positioning with participants

Ethical reflexivity is threaded through this thesis. The emphasis on relationship with all participants, particularly those considered vulnerable, required a thorough attentiveness to an ethical approach in every phase of this research experience (Denzin & Lincoln 2018; Dewing 2007; Heggestad, Nortvedt & Slettebø 2012). My reflective practice described above (Graham, Walton & Ward 2007) has formed and directed my values and ethics with respect to the person with advanced dementia.

In this thesis my understanding of research follows the National Statement on ethical conduct in human research, emphasising “the relationship between researchers and research participants” (National Health and Medical Research Council (NHMRC) 2007 (Updated 2018), p. 9). The researcher’s responsibilities therefore have a personhood focus that highlights respect, research merit and integrity, justice and beneficence. Relationships offered a context in which each person’s voice has been expressed regarding their past, their present, and their becoming as a conscious, perceptive and feeling person (Dewing 2002). All participants were viewed within a framework of ‘situated neighbourliness’, where researching with the person has been my positioning in collaborative, reciprocal, trusting relationships (Liamputtong 2022; Lincoln 1995, p. 287).

Throughout the field work regular meetings continued with my supervisors in order to maintain accountability. The principal supervisor was available to discuss any queries and concerns I had about the research process and protocols at any stage. At times my practical approach needed to change according to the fieldwork context and the participants’ circumstances. I discussed these changes with the principal supervisor and organisation’s supervisor. I also applied to the Ethics Committee for approval of the modifications. This awareness led to my personal ethical accountability with critical cognisance of my embodied enactments of words and actions, in the moment and retrospectively. This focus on the person “convey[s] respect and reciprocity” and also empathy (Novek & Wilkinson 2019, p. 1054), and enacts a research ethic of care throughout (Dewing 2002). Using “active participative ethics” (Scott Jones & Watt 2010, p. 9) has assumed and respected the agency of each person, particularly those with advanced dementia, for example in their ability to choose or refuse engagement with me. Throughout the fieldwork, analysis and write up, I have been aware of the faces, characteristics and contributions of the central participants, and also my ongoing positioning and respectful responsibilities to each one.

The following ethical principles summarise my research praxis, reflecting the concepts of person-hood, interdependence and citizenship (see Chapter 2) as foundational principles for the thesis.

- Each person's unique identity and agency require an attentiveness to providing opportunities of time and place to their self-expression in the moment-by-moment exchanges.
- Each person has an interwoven complexity of body, mind, spirit, and emotions as a whole human being. Therefore, there was an attentiveness to respectful and holistic care provided to the person to support their well-being.
- Each person has a unique spirituality that makes connections to all that is important to them. Therefore, there was an attentiveness to the person being able to express their spirituality in their own way.
- Each person lives in the aged care home in this phase of their life. This invited respect for the person as host, with the ability to influence what happened in each encounter, and my willingness to receive their hospitality.
- Each person is part of a community of inter-dependency offering mutual commitments for care and support. This created an attentiveness to each person being connected with others in ongoing relationships of mutual regard and interaction.

These principles guided the research parameters and my positioning towards those who were central to this study. These situated ethics reflect Coffey's emphasis (1999) wherein as a researcher I have lived with the paradox of being almost too familiar to participants within the context, due to my practitioner experiences. I have sought to achieve a limited, respectful naivety about the inhabitants and the variables in the fieldwork context, including the unique characteristics of each participant (Coffey 2018, p. 3) . However, researchers, including myself as a novice, recognise it is not realistic to entirely relinquish one's position of power and status (Laverick 2010; Scott Jones 2010). My "commit[ment] to not disempowering them" was a significant counter-balance in our encounters (Agar 2008; Coffey 1999, p. 44). Strengthening my commitment has been my intentional positioning which is multi-valent and refers to

> *the discursive construction of personal stories that make a person's actions intelligible and relatively determinate as social acts and within which the members of the [interaction] have specific locations (van Langenhove & Harré 1999, p. 16).*

The positioning of a person ascribes to them, positively or negatively, personal characteristics, capabilities and capacities. How I positioned myself in an encounter, implied my positioning of the other person(s). While divesting myself of power as researcher is not entirely possible, I have chosen the ways I have been positioned in relation to each person. For example, my positive positioning of the person has implied conversations and interactions regarding life's experiences have been mutually shared. The person has had equal status in being able to contribute and hear something of my storied-life. In forming relationships with one another I have developed and maintained “a moral sensitivity” as empathic attentiveness towards them. In so being I have been “touched both emotionally and cognitively” by the person with advanced dementia (Heggestad, Nortvedt & Slettebø 2012, p. 32). At times I have become aware of my negative positioning of the person, in overlooking their presence and overriding their capabilities and capacities. I have endeavoured to overcome my disregard of the person. Subsequently I have communicated my acknowledgement and appreciation of the person’s contributions, and recognised our reciprocal interaction in giving and receiving (Novek & Wilkinson 2019).

My research practice has been guided by Gardner (2011, pp. 105-7) with the reminder to engage in critical reflection, particularly when experiencing ambiguity and resultant discomfort. These times have been personally liminal, providing me with the opportunity to reflexively learn a new perspective from participants. I have developed skills in responding to the diversity of language of people with advanced dementia, including the verbal and non-verbal language in their gestured and embodied enactments. Engagement in the “interpersonal and intimate” nature of this research project has meant documenting how I made decisions throughout. Such reflexivity has led me to adapt to circumstances and describe this experience as and when it occurred (Coffey 1999, p. 55). Staying in the liminal space “between familiarity and strangeness” (Coffey 1999, p. 31), is part of the journey into the lived experiences of people. I endeavoured to navigate this as learning space.

Reflexive process in analysis

Reflexivity was also fundamental to the analysis and write-up phase of the thesis where I attended to ensuring the analysis was coherent and plausible. As researcher I continued to evaluate my assumptions and conclusions and keep abreast of current literature, including research findings and biographical stories of people with advanced dementia. I endeavoured to not engage in introspection for its own sake, but rather to support increased understanding, deeper insights and enhanced credibility of findings (Finlay 2002). I now turn to the methodological rationale for exploring the voice of the person with advanced dementia.

4.2 Qualitative Research

The framework for the methodology rests on the research questions and objectives.

The research questions:

- What are the ways the older person with advanced dementia expresses or enacts their voice?
- What enables the voices of older people with advanced dementia in residential aged care?

The research objectives:

- positioning people with advanced dementia as central participants and contributors;
- exploring their lived experiences in voicing themselves, and the significance this has for them;
- examining how the facilitation of family and staff members in a wide range of roles promotes their voices;
- exploring how the person's voice relates to their spiritual dimension, and how spiritual care praxis may promote their voice.

The qualitative approach to this inquiry stemmed from the philosophical and theoretical frameworks outlined in my ontology and epistemology, and specifically led to the choice of an ethnography. Seeking entry into another person's lived experience suggested a qualitative research paradigm to explore more closely the varied and detailed lives of people with advanced dementia in residential aged care. Qualitative research takes place in human settings and attends to the complexity and diversity of human experiences (Bryman 2016; van Manen 1990). Such research has as a guiding principle appreciation of the narrative dynamic and detail of people's everyday lives, from their perspective (Erickson 2018). By implication there is an underlying principle: a recognition that people ascribe their meaning and purpose for living to these experiences (Erickson 2018). These principles guided my research, centring on the person's presentation of themselves in their every-day life and what this means to them.

Qualitative research is formed in "the naturalistic perspective and interpretive understanding" of the lived and interactive experiences of people (Denzin & Lincoln 2018, p. 13). Epistemologically, this qualitative study was situated in the multi-faceted complexity of everyday interactions (Crotty 1998). Utilizing a range of methods for gathering and interpreting data, I became a participant along with the central participants and others, as co-constructors of the social context and its interpretations and meanings (Denzin & Lincoln 2018; Graham 2013; Sarantakos 2013). Qualitative research aims to construct meanings from the co-constructed data within the person and their wider context (Sarantakos 2013). This perspective has been foundational for this thesis in endeavouring to question the how and "to answer 'why' questions" relevant to peoples lived experiences (Silverman 2011, p. 17).

The research questions, objectives, and research context indicated the research methodology of ethnography which enables immersion into lived experiences and daily life. This approach embraced the individual and collective voices of people with advanced dementia, as well as their family members and staff (Liamputtong 2013; Picken 2013).

Ethnography

Ethnographic study has had a long history within the disciplines of anthropology, sociology and linguistics (Bryman 2016; Gray 2014; Jones, J & Smith 2017; Picken 2013; Scott Jones 2010). Early researchers including Malinowski in the 1920s, Margaret Mead in the 1940s, and Mary

Douglas in the 1960s, were anthropologists who lived within indigenous communities for extended periods. Their aim was to understand and provide a written account of a unique culture and its daily practices (Liamputtong 2013; Sarantakos 2013). As the practice of ethnography has evolved it has examined local settings, including organisations and collectives of people (Atkinson et al. 2001). Ethnography has embraced trans-disciplinary research, including issues of health care in ageing, practices and social systems, and factors contributing to well-being and wholeness (Delamont 2004, 2011). Ethnographies of communication and interaction in a specific context have sought to understand how and why these ordinary experiences of human life occur (Keating 2001; Saville-Troike 2003). Recent attention has focused on ethical factors in ethnographic research, notably the positioning of participants within the research setting, and attending to just, respectful observation of people's rights (Bryman 2016; Jones, H 2010). Researchers have adopted a more nuanced and relativist approach to their study in appreciation of the multiplicity of voices within a specific culture (Finlay 2006). The original ethnographic principles remain central; exploring deeply, broadly and extensively the characteristics and daily practices of people within their natural setting, and the unique cultural background to their lived experience (Liamputtong 2013; O'Reilly 2009).

As the researcher, I sought to enter deeply into the lived experience of the central participants, people with advanced dementia, to gain an 'insider's perspective' of their lived experience (Fetterman 2010, p. 21). Ethnography allows researchers to interact with and observe participants in their ongoing real-life environment. Ethnographic methods provide diverse ways to generate data (Liamputtong 2013; Picken 2013), enabling the input and perspectives of people with advanced dementia according to their individual capabilities and capacities and voice repertoire.

Participant observation

In undertaking an ethnographic study, I was aware from experience that people with advanced dementia respond to those with whom they have regular interactions, share familiar relationships, and have meaningful moments of connection. These occurrences happen intermittently and are not always readily observable or predictable. With access to each person only in public areas, I wanted to augment the times when I might encounter and observe them expressing or enacting their voice. I therefore chose a form of participant observation in which I was a "participating observer" (Bryman 2016, p. 435), actively engaging with people with advanced dementia in interactions and activities as opportunities occurred or were arranged. Consequently, I conceived my intervention as moving around and amongst people in shared areas, initiating contact, unless the person did first, and participating regularly in interactions and activities with them one-to one, and in groups. I gained ethics approval to 'shadow', that is, to initiate and be 'alongside' a number of people to first begin forming trusting relationships, and to participate in conversation and other interactions with them (Carroll 2009; Czarniawska 2007). Ethnography is embedded in an emic and etic approach to research. I have sought to navigate the delicate balance between the emic of closely participating in “genuine interaction” and relationship, and the etic of observing with “the critical stance” (Mesman 2007, p. 284). I anticipated that my engagement with each person, initially and ongoing, would offer them opportunities to express their voice in various ways. Initially, this strategy presented me with a dilemma. Because I was engaging with the person, there was the opportunity for the person to express their voice. However, I soon became aware that ongoing connection and relationships were necessary and even prompted each person in seeking my attention to engage with them.

The importance of relationship and researcher positioning

When people agreed to my becoming involved in their ordinary, everyday interactions and activities, my newness in the setting gradually developed into a rapport, and sometimes an ‘intimate familiarity’ (Agar 2008; Brewer 2000, p. 11). As relationships formed these invited a place and opportunity for people to express and enact themselves. Often this stimulated the positive responsiveness and pleasure of the person in their verbal and non-verbal language. This approach enabled the possibility of the relationship developing and even deepening between us (Brewer 2000). In this thesis I have sought to be transparent about the influence and effects of my role as an ethnographer throughout the fieldwork and analysis phases. I have explained this stance in two specific ways. I have declared my underlying ontology, epistemology and positioning in this chapter. In Chapters 6 to 8 I reflect on my participation and how this affected the person’s voice.

This fieldwork was not unlike the positioning of a pastoral practitioner. Being engaged in forming relationships with people begins slowly and takes time. Fieldwork, as in any meaningful endeavour, requires one to be invested and this includes in fostering relationships with others (Coffey 2011, p. 2). Nevertheless, remaining true to the parameters of my researcher role in the setting was important. For example, I did not provide ongoing emotional support, and instead referred a person to staff when appropriate. Recording observations and insights and making notes at the end of the day helped balance the objective etic stance with the intensity of the emic position during the day. However, Heshusius (1994) contests the notion of balancing objectivity and subjectivity as “an alienated mode of consciousness which sees the knower as separate from the known” (p. 15). I chose not to adopt the stance of distancing myself from the person in any particular way. I considered that distancing myself would not help me as the researcher to better understand the lived experience of the participants. Rather this would inhibit them from relating with me personally, and I with them. This study called for a sense of presence, attentiveness in the moment, and being ready and waiting to receive.

There has been a tacit knowing, not that I have understood totally, but of connection between each person and myself which may be described as

> *…[a] pervasive affirmative quality, which can exist only when there is a recognition*

> *of the deeper kinship between ourselves and other, [which] is the ground from which participatory knowing emerges (Heshusius 1994, p. 17).*

This research transcended the basic functions of methods to enact interactions that facilitated mutual engagement and relationships. Thereby my understanding and interpretations have become feasible and enriched. As the fieldwork has proceeded, balancing my positioning more towards the emic enabled the development of ‘thick description’ of the diverse interactions and observations (Geertz 1988; Picken 2013). As depicted by previous researchers, placing people and their voices in a widely descriptive context supports recounting people’s participation through the circumstances of episodes, verbatim quotes and descriptions of non-verbal language (Fetterman 2010; Liamputtong 2013; Light 2010). Thick description offers nuanced interpretation and meaning, and the recognition of cultural contributors or inhibitors to the person expressing their voice (Delamont 2011; O'Reilly 2009).

My personal and professional interest in spirituality recognised that the spiritual dimension for people is often “more meaningfully described than defined for…practice” (Jones, J & Smith 2017, p. 99). Each person’s expressions and enactments indicated what was important to them, who and what they were connected to, and what enlivened them. These features contribute to the person’s spiritual dimension and sense of well-being (Puchalski et al. 2014). This focus on the person’s spirituality added another significant aspect to the ethnographic study.

Strength-based inquiry

In their research into the British National Health System (NHS), Meyer et al. (2006) argued for a more trans-disciplinary and appreciative approach to research and practice development in residential aged care. This was a call: to value and listen to the voices of people living, visiting and working in aged care homes; to affirm strength-based and positive culture and praxis; and to overcome the negativizing and blaming mentality perceived in the general critique of the NHS (Meyer et al. 2006). This critique promoted an ongoing appreciative inquiry into practices being person and relationship-centred through the actions of collaborative learning, reflexive discussion, and continuous improvement (Meyer et al. 2006). In this study I deliberately chose a strength-based and appreciative approach to acknowledge the benefits in using a positive lens to uncover hidden competencies, and explicate ‘resources of resilience’ both in the central participants, people with advanced dementia, and in the diverse aspects of the organisation, including its staff and their practices (Mesman 2007, 2011; Saleebey 2009).

The Christian Scriptures encourage a similar focus on whatever is true, honourable, just, pure, lovely, gracious, if there is any excellence, if there is anything worthy of praise. This understanding of life and love serves as a transformative sign of God’s presence and peace in the world (Philippians 4:8). The Hebrew word for peace is shalom which has a deep relevance to this thesis:

> *…shalom means much more than tranquillity or the absence of conflict. The meaning is rooted in notions of completeness or wholeness…Shalom is God's dream for the world as it should be whole, vibrant, flourishing, unified. Shalom then is a biblically rooted social imaginary of holistic flourishing. Where everything within and between us…is put to rights by Christ, freeing us to become our true selves in communion (Hulme April, 2023).*

This thesis is founded on this social imaginary which perceives not only the positive features in the present situation and experiences of people. Also I consider the potential for further transformative possibilities emerging, that build on existing realities of strengths and competencies. Human beings in every stage are created in God's image to experience not only existence but human flourishing. While this reality of completeness and wholeness is not yet fully realised, nevertheless its potential is ever before us. This life-giving trajectory is the further impetus for this thesis.

In undertaking a strength-based and appreciative approach to research within the context, I have focused on those aspects of daily life, interactions, experiences and practices that enable, encourage and enrich the lives of older people with advanced dementia and everyone within the residential aged care setting. From this starting point a strengths-based perspective of each person focused on their continuing resources expressed and /or enacted in their voice (Brun & Rapp 2001; Kontos, P 2006; Saleebey 1996, 2009). Attention was given to the strengths, capacities, capabilities and resilience present within the organisation and its staff, which enhance the voices of people with advanced dementia (Dadich, Hodgins & Collier 2016; Mesman 2011).

4.3 Conclusion

This chapter has described the components that form and shape the methodology of this thesis. An outline of my ontology and approach to epistemology blended with principles of theological reflection and ethical reflexivity have provided the methodology's theoretical underpinnings. This foundation provides a rationale for a qualitative research process and implementation of an appropriate ethnography. My bricoleur approach has drawn together diverse notions of a strength-based approach to inquiry and of human becoming to cohere together in forming a methodological orientation to this project (Denzin & Lincoln 2018; Kincheloe, McLaren & Steinber 2011). Becoming a researcher has required creative engagement, metaphorically as a quilt maker, with a range of materials appropriated to piece together this thesis. This methodological framework has facilitated the principles of genuine relationship with and respect for the person with advanced dementia.

With my research interest in how the person's voice relates to their spiritual dimension and spiritual care praxis, ethnography and the associated theoretical notions have offered connections through "thick descriptions" and possible interpretations. This methodology offers a multi-dimensional interpretive lens, to bear witness to the voices of people with advanced dementia and their lived experience. The elaboration of this methodology provides a segue into a description of the research journey. Chapter 5 clarifies the practical aspects that enabled the person’s assent to engage with me within a respectful and reflexive process. This chapter also delineates in detailed narrative form, the bricolage of methods used to generate and analyse the diverse forms of data that were co-constructed through the fieldwork study.

CHAPTER 5 TRANSLATING METHODOLOGY INTO PRACTICE

Introduction

The previous chapter described the theoretical underpinnings and background of the research methodology and design and how this will influence analysis and interpretation. This chapter describes how the selected methodology was enacted in practice. The ethnographic methodology allowed a range of ways to co-construct data with participants. I was able to observe the context in which the participants lived, become part of their daily activities, and interact with residents, staff [5] and family members. Details of the Ethics Approval process (see Appendix 3) gives close attention to the special case of persons living with advanced dementia. The chapter summarises the actions that were undertaken to answer the research questions and realise the research objectives.

Research Objectives:

- positioning people with advanced dementia as central participants and contributors;
- exploring their lived experiences in voicing themselves and the significance this has for them;
- examining how the facilitation of family and staff members in a wide range of roles promotes their voices;
- exploring how the person’s voice relates to their spiritual dimension, and how spiritual care praxis may promote their voice.

I used strategies that ensured the inclusion and safe participation of the person with advanced dementia, not only as “a means of affirmative action but also for [accountability] and quality assurance purposes” (Dewing 2002, p.168). A detailed account of the fieldwork offers a supportive rationale based on rigour and accountability, and is directed towards the veracity and potential for transferability of this research.

Methods that become research actions operationalised the ethnographic methodology (Cupit, Mackintosh & Armstrong 2018). These methods are many and varied, and follow a stage-by-stage process of the research trajectory to fulfil the strength-based and appreciative approach of the thesis. The titles for each section in this chapter cover the beginning of the fieldwork through to the analysis phase. I begin this chapter by articulating my research plan.

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[5] Organisational policy stipulated that people who worked in the organisation were staff, whether they were volunteers or paid (OA).

5.1 Research Plan

My initial overall plan in this research study was to engage with older people with advanced dementia, who resided in the high dependency dementia unit of two aged care homes (RAC). The study would explore, through interacting with, listening to, observing and being with older people with advanced dementia, and the ways in which they expressed and enacted their voices. The aim was to understand the meanings and significance they each gave to having their voice. The exploratory approach was to 'shadow', that is, to be 'alongside', up to fourteen residents to develop trusting relationships first and foremost, and to participate in dialogue and other interaction with them. I also planned to engage with their family members and up to fourteen staff involved in their daily care to gain their perspectives of how the person expresses their voice. Consequently, as the researcher I would be inviting residents and others to participate in relationships, interactions and group activities with myself.

Initially I would be present amongst the residents to begin forming relationships with them whereby they indicated their assent or dissent to being in this relationship, and to participating in the study. Subsequently I would ascertain whether the substitute decision makers, of those residents who assented, consented to the involvement of these residents. Process consent procedures would be used to assess the initial and ongoing willingness of individual residents to participate (Dewing 2002, 2007). I would utilise a range of ethnographic methods to provide opportunity for participants to express their voices in diverse ways within their context including: audio recording of one to one and group conversations, participant observation of "central participants" in conversations and interactions; and the noting of participating resident's progress notes. The settings for the study were to be the places throughout the memory support houses where residents spent their day, as they sat or moved around, including the dining and sitting rooms, passageways and gardens.

5.2 Contacting the Organisation

In discerning potential fieldwork sites, I approached a not-for profit residential aged care organisation with several homes across Adelaide, South Australia. This organisation was separately incorporated as an agency within a religious denomination. All the Homes, as part of the one organisation, had the same religious affiliation. I was not employed by the organisation, but a previous professional relationship facilitated its initial expression of interest to my undertaking fieldwork within this organisation. Therefore I did not seek other possible organisations in which to conduct the research. In a meeting to introduce the research study to the Executive Manager, I presented the topic, research questions, underlying ethos, and an overview of how I envisaged undertaking the research with people with advanced dementia, their family and staff members. Concurrently in late 2016, the Australian aged care sector was entering an extremely challenging period. Through secretly obtained video footage the media exposed abusive and neglectful practices in both government and privately run facilities, resulting in the Royal Commission into

Aged Care Quality and Safety (see Chapter 2). I was aware of the heightened sensitivity to proposing my research with the organisation. I outlined the proposal for an ethnographic research design (see Section 5.6), and explained this approach verbally and in writing.

The designated Executive Manager commenced an affirmation protocol and expressed the organisation’s willingness and support for the research design. I was granted permission to conduct research at two of the organisation’s sites. The fieldwork was located in an organisation where I was not the chaplain and with residents with whom I had no prior relationships. Throughout the fieldwork phase my PhD principal supervisor oversaw the details of my research project and any issues that arose. I made several progress reports to the delegated Executive Manager. The Residential Services Manager (RSM, see Definitions of Staff Roles and Terms) of each home was delegated with the day-to-day management of the project. With the overall arrangements for the fieldwork in place I commenced the process of gaining ethics approval.

5.3 Applying for Ethics Approval

In Australia the National Health and Medical Research Council ethical guidelines (National Health and Medical Research Council (NHMRC) 2018) refers to people with cognitive impairment being entitled to involvement in research. Section 4.5 of the Council’s National Statement on Ethical Conduct in Human Research, 2018 states the regulations for the participation of persons with a cognitive impairment. Peak body, Australia Alzheimer’s (2004) states that to exclude people from research, who are otherwise eligible, based on their lack of capacity to consent is discriminatory and further marginalises them.

Application for ethics approval to Flinders University Human Research Ethics Committee (HREC) highlighted the sensitivities in researching the vulnerable population of people with advanced dementia and took eight months. Four ‘conditional’ responses required further detailed information regarding research protocols. Each submission confirmed the non-coercive involvement and protections for people with advanced dementia and their families. The HREC emphasised the specific needs and, explicitly, the limitations of people with advanced dementia, noting that each person could tire easily, might lose concentration and become uncomfortable after a short time. I was therefore required to limit every individual interaction to only five to twenty minutes, and to arrange a maximum of three sessions.

The application process gave attention to gaining the consent of people with advanced dementia in addition to the informed consent of the family participant who was substitute decision maker. Process consent, with its accompanying assessment of the person’s well or ill-being, was approved by HREC as the primary mode for establishing consent (Dewing 2002, 2007). In this study, respect for a person’s right to consent to participate preceded the legal requirement of gaining the informed consent by the person’s substitute decision maker (Dewing 2002). Founded on an ethics of equality, justice and inclusion, and person-centredness, this method is consistent with this thesis' emphasis on an ethical reflexivity focused on the inclusion and participation of the person with advanced dementia. Dewing's model does not require cognitive decision-making on the part of the person with dementia. Instead, the model details the rigour of ethical of gaining and maintaining the person's positive engagement with the researcher as assent to participating in the fieldwork (Dewing 2007).

Throughout the fieldwork, I adhered to the ethical research protocols and procedures. I endeavoured to remain person and relationship-centred with people living in the aged care home, families and staff, and to follow an ethics of care. This involved: attentiveness through openness and recognition; responsibility through meeting needs related to the research and/or appropriate referral; competent, responsive care for each person; recognition of the responsiveness of the person; and solidarity through trust and empathy (Brannelly 2016, pp. 307-8; Tronto 1993). the formal ethics approval gave some flexibility to adapt my procedures to the particular setting, for example, in ways to meet with family members to seek their informed consent. Of prime importance was my attentiveness to the needs and choices of each of the participants, particularly people with advanced dementia. How these methods were implemented in the project will be discussed in section 5.5. Once ethics approval was obtained (See Appendix 3 Ethics Final Approval Notice, Project No. 7552), I commenced the fieldwork phase of this study.

5.4 Locating the Field Sites

A preliminary meeting at each site introduced the organisation's fieldwork supervisor, the residential services manager (RSM) (see Definitions of Staff Roles and Terms) to myself, and established research protocols and practicalities such as access to an office and other places.

On my initial day at each home, I met with the Care Coordinator (see Definitions of Staff Roles and Terms) who welcomed me, gave an orientation tour, informed me verbally of occupational health and safety rules and procedures, and gave me a folder of site information. Each Care Coordinator indicated my right to access most areas, provided this was acceptable and appropriate to the people within them. Subsequently, I always asked a senior staff member and people within the house for permission to enter any of the areas. When not permitted, I was courteously given reasons for this.

Table 4 Summary of Fieldwork

Methodology: Ethnography
Central participants- Interactions-conversations, participant observation one-to-one and in groups, social and spiritual care plans, artefacts in own room **Family members-** semi-structured interviews, participant observation **Staff members-** Semi-structured interviews, observation of practices and organisational practices Researcher- Participant-observation notes, Reflexive journal
Field sites
Same medium-sized aged care organisation 2 aged care homes in the suburbs of Adelaide, South Australia
Participants
Central participants- Ethics Submission 14 Later approved Field Work: 24, Home 1: 10, Home 2: 14 Exemplars: Home 1: 3 men, 1 woman, Home 2: 5 women, 3 men Family members- Ethics Submission: 14, Home 1: 7, Home 2: 7 Exemplars’ family members: 9 Staff members- Ethics Submission 14 Later approved 29, Home 1: 12, Home 2: 17
Time Frame at Homes 1 and 2
Seven-month period during late 2017- mid 2018. Prior to Covid-19 Home 1- 26 days (8 hrs/day), December-March > 208 hours Home 2- 28 days (8 hrs/day): June-August > 224 hours

Descriptions of the organisation’s ethos and culture in each home

The organisation prided and promoted itself as providing excellence in its delivery of holistic care, and in the planning and presentation of its buildings, furnishings, and surrounding gardens. As the Australian Royal Commission into Aged Care Quality and Safety determined not all residential aged care aspired to nor fulfilled these standards. So in this regard this organisation may be perceived as representative of above average services and features in residential aged care. Consistent with these aspects was its integrated model of care which espoused and sought to exemplify a culture of encouraging each person, be they a resident, their family or staff member to make the most of each day, and continue to experience well-being during this phase of their life. While the organisation did not articulate a particular religious stance, organisational documents profiled the espoused ethos and culture of the organisation and its homes, to residents, families, staff, visitors and members of the public. This ethos and culture were encouraged through: ongoing staff training, mentoring by management, and consistent reinforcement of respectful personhood values, language, and performance regarding the provision of services to the organisation's "consumers". In each Home I considered that staff supported people to communicate their voice in relationships, interactions and activities, and through expressing their choices, lifestyle preferences, and agency. People appeared to be facilitated in contributing their voice and expressing their capabilities and capacities in a relational and social environment.

Descriptions of the physical layout of each home

Home 1 (Home 1, POD, Book 1) *(see Glossary of Abbreviations p. xiv)*

Home 1, a multi-level building where approximately 80 residents lived, was built in the 1950s with long corridors of doors to each resident's room, interspersed with dining and lounge rooms. Communal areas were furnished with comfortable seating and included lounge rooms, a spacious dining room, chapel and café-courtyard, large entrance areas, and gardens, some for dining, and others for group activities and special events. Not all the Homes within this organisation, nor all organisations with a religious affiliation in Australia have an allocated chapel. If the organisation incorporates a specific chapel in its buildings, many Homes use this as a multi-functional and activities space, as was the case with Home 1. The main lounge and dining rooms were recently refurbished. I observed many residents in the home walking to these places, asking to be taken there, or staff moving them there, to sit, relax and chat in the company of others, or on their own observing others.

Residents, families and staff moved around the building via stairs at either end of the corridors or by a central lift. External doors were secure but there were no separate memory support houses (see Definitions of Staff Roles and Terms), and people with advanced dementia lived throughout the home. Each person had access to all communal areas within the building and the garden courtyards. Many who could walk moved over long distances into various areas through the day.

Home 2 (Home 2, POD, Book 2)

This much larger site had approximately 120 residents. Its physical layout was quite different, built on one level and occupying an elongated building footprint. Four houses were each separate units, joined by a central passageway. Each house was named, and had a kitchen, dining room, lounge room and private rooms around a passageway. These houses accommodated those living with advanced dementia, providing private rooms, shared places and care for approximately 42 residents. Internal doors to two of the houses were secured. Within these houses residents sat or moved about in various places including their private room, the dining-lounge room and another smaller sitting room, an adjacent bigger activity room, and an adjoining large courtyard garden with a long pathway. Each area was furnished with comfortable seating. This Home did not have a Chapel but a common area was used for church services twice a week.

5.5 Recruiting the Participants

The fieldwork was introduced to all staff, residents and/or their families through each home's regular newsletter and information brochures left in reception areas and staff meeting areas. Instigated by each Residential Services Manager (see Definitions of Staff Roles and Terms), each staff member received a staff memo about the fieldwork. This information paved the way for my initial recognition by some residents, family members and staff. I still introduced myself and the project each time I met a resident, family or staff member.

I identified people with advanced dementia in a variety of ways: the recommendation of a staff member and then being introduced; noticing a particular person to whom I then introduced myself; and later verification of those with a diagnosis of dementia and high care needs in all three domains according to the ACFI assessment (see Definitions of Terms) by the Care Coordinator. This varied approach brought me into initial contact with many people with advanced dementia.

People with advanced dementia

In gaining the consent of people with advanced dementia I implemented the Process Consent method with a step-by-step protocol of practical procedures and documentation as follows (Dewing 2002, 2007; Scottish Dementia Working Group 2014).

Step 1: Preparing background

At the beginning of the fieldwork and on each occasion in a particular house or area, I checked with staff, or a family member with their relative, that I could access the place and the person at that time.

Step 2: Meeting initially

First contact occurred when residents were observed to be in a state of well-being, that is they appeared calm and relaxed. I approached the person with respectful distance, and gently offered respectful rituals of greeting verbally and/or non-verbally, thus forming some connectedness with each person and building trust. I looked carefully for initial assent in their signs of engagement and comfort such as a turning towards me, a smile or other 'interested' facial expressions, brief verbal comments or sounds. However, when a person indicated no desire to engage, for example with "No" or turning away, their response indicated dissent and I courteously took my leave, ensuring they were in a state of well-being. Only three people declined using one of these responses. As part of my ethics' protocol I respected each person's choice as to whether they wished to relate to me or not. In their response they were also expressing their voice. Some people were naturally shy and /or suspicious of me as a person they did not know, or they only wanted to relate to certain members of staff who were familiar. Most people appeared to want to engage with me when they were in state of well-being.

If a person gave assent, I returned the same or next day to develop the relationship further. This initial assessment was recorded on a Process Consent Assessment Instrument form (see Appendix 7 Process Consent Assessment Instrument for Each Central Participant).

Step 3: Establishing a basis for consent

Process consent considers the competency of the person to make decisions. Through conversations with several staff and/or the substitute decision maker, I ascertained the visual, auditory and other signs each person used to indicate: usual self-presentation; usual level of well/ill-being; decrease in their level of well-being, and what events might trigger this response; how the person usually consented to activities and procedures within their day-to-day life; an introductory biography of the person. I documented this information on each person's Process Consent Assessment Instrument form (see Appendix 7) and included my observations of the person after each time we met: the date, specific details of my contact with the person, and a well-being score of -5 to +5, similar to dementia care mapping (Brooker & Surr 2006).

Step 4: Ongoing monitoring of consent

Each time I arrived in a particular house/area I checked with a staff or family member regarding access to a person with whom I had had initial contact. Some people who had dissented initially indicated their assent later as I became familiar and carefully approached them. The person's assent or dissent to participate always remained paramount. Their response towards me and their well- or ill-being, determined whether I would proceed to engage with the person. If, according to their identified signs, a person was in a state of ill-being I would not attempt to approach them. However, over time I found that if I greeted the person, they might respond with signs of wanting to engage, for example, reaching out a hand or turning towards me physically and/or with their gaze. I would then continue with the person, observing whether they again expressed ill-being. I also noted that as some people came to know me, they occasionally sought my company when in a state of ill-being. I sometimes simply sat with a person when upset or restless and they would engage with me. Sometimes their mood would elevate, indicated by a calmer facial expression and/or their ongoing sounds or words.

Occasionally as we interacted they might become upset, seemingly due to their inner state and/or memories elicited. Again, I would remain with them, listening, supporting and empathising, and this often calmed them. I would then refer the person to a nurse for support or assistance. An ethics requirement and also an undertaking with each RSM, was that I refer anyone who seemed to indicate a concern to the nurse in the house (Dewing 2007, p. 17). If the person ever dissented I courteously left, ensuring they were in a state of well-being. Within any group setting the assent of each person was always necessary. While courteously relating with each person, any involvement of those who had not previously assented to engage with me was omitted from the data of that particular event.

Step 5: Offering reciprocal feedback and support

A nurse or another staff member would discuss with me how a person was on a particular occasion. I would briefly convey my perceptions of a person's well-being or discomfort, but I did not divulge personal details entrusted to me by the person unless this directly impacted their care. Occasionally, having concluded an episode of engagement, a staff or family member would affirm the time spent with the person by me. We would also share insights about reasons for this positive engagement, to encourage staff or family in their ongoing interactions with the person.

In my participant observation diary (POD, Book 1 or 2) I noted any issues of concern for discussion in regular meetings with my primary supervisor. During the fieldwork this reinforced accountability and review of my research practice. For example, I recognised reflexively after an interaction or interview when I was taking over a conversation with a person or a family member. Other issues were infrequent due to following the ethics protocols, procedures and courtesies within each home. I became increasingly aware of differentiating my role as a researcher from that of a pastoral practitioner. I chose when it was appropriate to engage with a person or not, according to the signs the person gave. I also respected how the staff worked in the setting, observing boundaries such as only taking over their responsibilities through negotiation with them, and within my research capacity. I endeavoured to be appropriately attentive to the ways that each person, resident, family member, or staff member, wished to relate with me.

Substitute decision maker's consent and participation

In South Australia the Advance Care Directives Act 2013 (SA) legislates and clarifies the legal power of the substitute decision maker to represent the person as signatory, if the person is unable to retain information relevant to the particular decision (Advance Care Directive Act 2013 (SA), s7 (1)). Therefore, in addition to the process consent of the person their substitute decision maker signed an Informed Consent form (see Appendix 8) for the person's involvement in the research project. I ascertained from the substitute decision maker of each person who had given assent, whether they gave informed consent to the involvement of their relative. The person was then considered a 'participant'. Ethics approval required that no one felt coerced into being involved, so I adopted two methods to obtain the consent of substitute decision makers, and appropriated one to each site.

Firstly, in Home 1 I found out when a substitute decision maker was likely to visit their relative, so I could introduce myself and offer a ‘Letter of Introduction’ (see Appendix 5) and an ‘Information Brochure’, including a ‘Reply Page’ (see Appendix 6). They were free to take these if they wished and make a later decision regarding their relative or themselves participating. If so, they could later fill in the Reply Page and place this in the sealed box at Reception marked “Research”.

Secondly, in Home 2 I could only make contact face to face with a few substitute decision makers during my hours there. Following protocols, I asked the RSM if her assistant could email the substitute decision maker of each person with whom I had begun to form a relationship. A brief email was sent stating the nature of the research project, and that the substitute decision maker could obtain further information through the ‘Letter of Introduction’ (see Appendix 5) and the ‘Information Brochure’ (see Appendix 6), available at the front counter when visiting their relative. Of their own volition, some substitute decision makers gave their consent by a return email. I responded, asking that on their next visit they fill in the ‘Reply Page’ form in the copy of the Information Brochure at the front entrance and place this in the box marked “Research”.

In both aged care homes, I outlined to each substitute decision maker, both in the documentation they received and verbally, that they were free to respond if they wished to participate with no compulsion by me or organisational management. I reinforced that the data regarding their relative and themselves would be de-identified. I received the informed consent of the substitute decision maker (see Appendix 8) for each person to participate with whom I had assent and a developing relationship. All the family members who became participants were substitute decision makers.

Staff members

Using initial information disseminated to staff through the RSM’s staff memos and newsletter and with the permission of each RSM, I placed copies of the ‘Letter of Introduction’ (see Appendix 13) and ‘Information Brochure’ with ‘Reply Page’ (see Appendix 14) in the staff dining room and on staff counters. During their workday and in breaktimes many staff expressed an interest in the research. Only paid staff occupied the staff dining room through their shift, so I introduced myself to voluntary staff in the area where they worked. When a staff member wished to participate, I asked that they fill in the ‘Reply Page’ inside the Information Brochure and place it in the Sealed Box marked ‘Research’ in designated places. I contacted these staff members by their phone number or in their next shift to make an appointment. I outlined to staff, both verbally and in the brochure, the research protocols and that the data relevant to them would be de-identified.

5.6 Generating the Data

The research methods allowed for “multiple sources of information” to explore and understand each person’s experiences, and particularly their voice within their social context (Liamputtong 2013, p. 172). Participants were involved in the research as outlined below.

People with advanced dementia: key informants

I became immersed (Liamputtong 2013) with each central participant by adopting the role of participant observer (Bryman 2012; Watt & Scott Jones 2010), that is, being ‘alongside’ people in the course of normal activities to develop good relationships (Agar 2008). This meant being respectful, humble and ethically attentive.

‘Key informants’ in an ethnographic study are the significant contributors to a research project (Bryman 2012; Liamputtong 2013) due to their competence as “native speakers”. They have their own language in giving information, and become the “teachers” about their lived experience and their context (Liamputtong 2013, p. 173). In this research people with advanced dementia became the key informants, each expressing themselves in their personal voice repertoire (Ellis & Astell 2018) which I endeavoured to become familiar with and appropriately mirror. In our times together, according to their individual characteristics, capabilities and capacities, each person provided information about their lived experience and situational responses. I began to understand the daily ebb and flow of their lives, and prepared questions to be asked later both with them and others (Agar 2008; Bryman 2012; Liamputtong 2013). This level of interaction enabled relationships of respect, familiarity and reciprocity to develop (Bryman 2012). During these encounters my experiences and expertise as a chaplain supported my specific objectives as the researcher (Downs & Collins 2015; Nolan et al. 2002; Wilkinson et al. 2015). I incorporated the insights of McKillop, a person living with dementia and a researcher with people living with dementia. McKillop gives practical guidance on topics such as “getting consent; issues of comfort; building relationships…and exiting gracefully” (McKillop & Wilkinson 2004, p. 118).

Encounters took place wherever participants spent their day, as they sat, or moved around. Data were generated through conversation-interaction, participant observation, and participation in group activities together. This process enabled the person to contribute their voice however they were capable and comfortable and in diverse situations (Agar 2008; Bryman 2012). Being together during their day enabled each person to be engaged in the ‘doing’ of their voice. These encounters were not preparation for a later interview, but the actual times of being informed by participants, their initiatives, lived experience, perceptions, ways of interacting and communicating through their day. For instance, a person might tell me their stories and ask me about myself, or indicate their immediate need. A couple of people would chat, joke, and laugh with one another and include me. A person would help another person or myself, and yet another sang with me. During interactions, group activity or family interview, with the participants’ assent I used an audio-recorder to record their talk and describe their non-verbal movements verbally for later transcription. I also made observation diary notes after engagement and journal notes at the end of each day, and then downloaded all the audio-tapes onto my password protected laptop.

When I faced choices that were not part of the ethics application protocols I discerned an appropriate decision in the moment, according to the well-being of the participant. I subsequently made a Modification Request to the Ethics Committee for approval to change my original protocol. These modification requests were later approved by the Ethics Committee. I now give two examples of this modification process. Due to acknowledged vulnerabilities and limitations, the initial ethical protocols limited encounters with central participants. However, as we developed relationships with one another many participants indicated a desire to spend more and longer times with me. I applied for and received a modification approval allowing for longer occasions with no limitation on the number of encounters, while remaining attentive to situated signs of capacity of each person (see Appendix 4). This modification recognised the agency of each person in articulating their need for further connection in meaningful relationships. At the time I was reminded of the earlier statement that efforts to protect the person with cognitive impairment in research, while absolutely necessary, may further prevent them from having their voice, and privilege processes of cognition and the written word (Australia Alzheimer's 2004). As field work continued people who were mobile would of their own volition, recognise and approach me, and seek to develop our relationship further. Some people in comfort chairs (see Definitions of Staff Roles and Terms), upon seeing me nearby, would look at me and gesture, with a facial expression, word or sound. If they were not able to see me or had limited movement, I would speak quietly, and if appropriate to the person, touch them gently to simply offer a greeting. In response the person would sometimes reach out their hand to me or utter a sound or word. I would reciprocate with some verbal or non-verbal movement and we would spend time together as they indicated (Foley, Pantidi & McCarthy 2019). The person usually did not appear to tire, but engaged with me throughout, or we would sit or walk companionably in silence**.** If they appeared to tire I would take my leave courteously, ensuring I left them in a state of well-being in a comfortable situation. If I attempted to leave too soon according to the person, they would react negatively and indicate with sounds or words their desire to continue being together. Once again I made a Modification Request to the Ethics Committee and gained approval to increase the sample size for central participants to include more people who indicated their desire to relate with me.

My initial research plan remained mostly intact as my overall guide for undertaking the fieldwork, and cohered with the resulting research. My decisions about how this plan would play out with each participant needed to be flexible, and the ethics approval allowed for this. This decision process was according to their well-being, choices and circumstances in the moment, and whether they were able to remain a participant in the study should their circumstances change. An example of a situation that required a change in plans was the sudden onset of the end-of-life phase or death of four people with whom I had begun to form a relationship. This occurrence was prior to my obtaining informed consent of their substitute decision maker to their participation. In these situations I discerned it to be inappropriate as a researcher to contact family. This was a point of differentiation between my role as pastoral care practitioner and researcher, and a growing edge for me in this study. Nevertheless, I experienced at these times some sadness and disappointment that these people's stories and contributions could not be included in this thesis.

Data from other sources included each person's social-spiritual care plan (RCP), interviews with their family member, and specific comments of staff regarding their care. In this organisation documentation of each resident's social-spiritual care plan included a social care plan written by the Lifestyle team, a history or life story by the Lifestyle team in collaboration with the Chaplain, and a spiritual care plan written by the Chaplain. The extensive compilation of a detailed audio-taped and written description in the care plan enabled the development of "thick description", a rich account of the person and their voice in their setting, and identification of those factors promoting the voice of each person (Bryman 2016, p. 384).

Participant observation

As participant observer I engaged in a variety of activities, including having refreshments and lunch together as we chatted, attending small social and activity groups, or a larger group such as exercises or a church service (McGovern 2016). These varied activities lasted up to fifty minutes and were noted briefly in my POD during the session. Due to the immersed nature of being alongside people, I found there was overlap and complexity for me in performing a variety of fieldworker roles, for example moving from participant observer in a group activity to interacting one-to-one with a person when sequential events took place (Bryman 2012). I was also aware of the need to plan my time to make the most of opportunities for engagement while also being flexible to go with the flow. I endeavoured to be respectful and non-intrusive and to sit back and simply observe at times, while I also recognised when I was being invited to engage (Bryman 2016; Gray 2014). Each scenarios meant being part of the ebb and flow of communal and individual life, and being attentive and attuned, while also taking time to be apart to reflect and rest.

I adapted an observational tool based on Dementia Care Mapping (Brooker & Surr 2006) (see Appendix 9) to be relevant to the physical areas and activities of each of Home's areas in which central participants spent their days. This tool was a list of seventeen facets with which to observe each person's interactions and participation in activities with others (Brooker 2008; Brooker & Surr 2006). The Bradford Dementia Group (UK) initially developed Dementia Care Mapping (DCM) in 1997 with specific person-centred protocols and procedures to evaluate a person's unique needs, movements and activities in the setting and to equip clinicians in providing appropriate care (Mansah et al 2008). Kitwood (1997) described DCM as "a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill" (p. 4). Resonating with these comments, This enabled the documentation of a detailed description of the ways each person expressed their voice in their particular setting (Liamputtong 2013; O'Reilly 2009), including daily routines and interactions and group activities, apart from personal care and hygiene. I observed the effort and enthusiasm several people put into making their contribution in these occasions with others. After each session my observations were written up in my POD and summarised with my commentary into each person's Observational Grid (see Appendix 9). I recorded my role(s) in each situation to assist me in being self-reflexive about my involvement with each person (Reinharz 1997). This recording procedure became an ongoing form of analysis, used later in the analysis process after fieldwork was concluded (see Section 5.8).

Semi-structured interviews with family members

One objective of this study was to interview family members to identify the ways family and friends recognise and facilitate the person's voice. Some family members chose to be interviewed separately, considering their relative might become unsettled by the interview. The majority of family members chose to be interviewed alongside their relative, with the person engaged in our conversation and making comments verbally and non-verbally. This suggested that the person and family member were used to relating in this way to one another, since the person demonstrated their capacity to follow the conversation of others and make apt responsive comments. Semi-structured interviews with a guided list of questions (see Appendix 12), allowed for flexibility (Bryman 2012; Liamputtong 2013). Knowledge was co-constructed, with many interviews being more like an in-depth conversation (Bryman 2012; Sarantakos 2013), respectfully going to where the interviewee wished (Heyl 2001). Some asked me specific questions concerning their loved one's condition and situation. I would indicate my lack of clinical expertise and provide support in response to their feelings, and considered insights from my growing knowledge regarding the person and their voice. Family also commented about the care which they observed specific staff giving to their loved one.

Retrospectively, I became aware that my responses were framed as those of a spiritual care practitioner rather than a researcher. As I listened to and was questioned about issues uppermost to the family member, I was aware that they were often not specifically responding to my questions. I realised during these interviews that many family members responded this way because they simply needed to talk about their issues regarding their loved one and their condition. They seemed to value the opportunity to talk through their concerns, uncertainties and lack of knowledge. It was apparent that several family members were unable to contribute their insights about their relative's voice, except that it was "not like it used to be", and even "goobly-gook". I sensed their grief and loss and recognised our conversation as the family member's opportunity to speak personally and receive reciprocal support in giving their perspective. This factor in the family's lived experience was included in the data analysis as it related to the person's voice.

Semi-structured interviews with staff members

Most interviews with a participating staff member occurred after we had started to develop some rapport and trust, and in a place they chose. Insights gained through the literature search and previous personal and professional experience informed the preparation of the Questionnaire Guide for staff, who varied in their ability to reflect on the person's voice. However, all who wished to be interviewed indicated their enthusiasm and dedication regarding their caring role with people. Interview guide questions for staff were not trialed beforehand. However, as I used the guide over time with more staff members, I became more adept at adjusting the questions and using probes to elicit their responses. With this interview guide (see Appendix 16) I invited staff members to reflect about their engagement and facilitation with people and their voices in specific situations and generally. Interviews lasted fifteen to forty minutes, and were usually only once. Six staff members chose to be interviewed a second time and provided detailed examples of their care with particular people who were research participants. Most staff freely set their interview time after their shift, by phone call or by coming in on their day off. Their desire to be involved in the research indicated their enthusiasm and dedication regarding their caring role with people with advanced dementia. Probes were used spontaneously according their responses. Their participation revealed their interest in the topic, its relevance to their role, and their embodiment of prompting and listening to the voice of the person already. Significantly, by being interviewed and observed in their work, these staff demonstrated their commitment to and compassion for the people in their care, and their desire to talk about the importance of their work, and make their contribution to this research.

Dual sources of data, interviews and observations, allowed for a comparison of the comments and practices of staff members (Bryman 2012; Sarantakos 2013, p. 159). Even if not wishing to be interviewed, many staff members gave their consent to being observed in their interactions and direct care with residents. Several staff expressed their appreciation that I did not come just to observe, but that I spent time listening to them, and relating with residents in one-to-one and group activities as a fellow participant. My stance gave me opportunity to sit with staff in their dining room, be part of conversations and listen to them debrief during the day.

Beyond my original expectations, at each home people came forward to participate. I made a Modification Request to the Ethics Committee to increase the number of central participants and staff members which was approved.

5.7 Leaving the Field

In developing relationships over time, people and I enacted a range of shared social rituals. These rituals are well-known, embodied habits for people with advanced dementia due to their life-long experience of them (Muller & Mok 2014; Watt 2010). The ritual of final farewells was significant as a formal courtesy that signified to each person and the community that fieldwork had ended. This was the occasion to celebrate the time we had shared, to express our reciprocal gratitude, and to say our goodbyes. I had informed the organisation's management and supervisors of my completion date. The RSMs and leaders in each home also recognised the need to mark my time with a farewell event. This event happened similarly in each home was but with different outcomes.

Home 1

A singalong was organised by the Lifestyle team and myself to be held in the big lounge room, facilitated by the lifestyle assistants. They and I informed residents, staff and families of my imminent departure and advertised this event. The day prior to the event I spoke with each person who had participated. Some chose not to attend, and we affirmed our time together and said goodbye elsewhere. For example, one person seemed surprised I was not permanent when I said I was leaving, and was briefly sad. She then asked if lifestyle assistant Anthea, with whom she shared a close relationship, would be there and she was happy.

The farewell singalong was an enjoyable afternoon, singing together with LAB, Anthea playing the piano, and comments of gratitude from a resident, staff, and myself. The concert included the performance of an Italian aria by Thomas and I, since his daughter had told me it was his favourite. Thomas whistled the melody perfectly and I sang. At the end Thomas and I looked at one another, and Thomas exclaimed, “That was beautiful.” and I replied, “It was. Thank you, Thomas” (AT, RI, LRm, Thomas, 9/03/18). I ensured I said goodbye to everyone that day. I did not return because the transcripts and signed forms were delivered in an envelope later to Home 2 for me to pick up. As I moved around the home in the last few days, I affirmed staff members for their support of people, and specifically my fieldwork. I also shared any concerns I had about leaving particular participants with the Lifestyle Coordinator Prue.

Home 2

We planned a similar farewell singalong in Home 2. However, before my concluding date the event organiser went on leave, and I became ill and was absent for a week. In the last days I moved around the home telling everyone I was leaving and thanking them for having me. We rearranged the event which seemed to be enjoyed by all, and I gave my thanks to everyone. However, the event seemed not to have the same finality as in Home 1 since I needed to return to collect the transcripts left by staff and family members from Homes 1 and 2. I was greeted by several staff warmly and they told me that some who had been participants had been sad at my leaving, and also that some had since died. This experience reinforced to me that some people with advanced dementia feel the loss of someone with whom they have developed relationship, and the need for ongoing relationships with others for sustaining the well-being of people. I realised again the importance of making the present moment count as worthwhile and significant in the lives of people in this last stage of their lives.

5.8 Compiling the Data (see Glossary of Abbreviations p. xiv)

The management and analysis of the data sets was an ongoing process during the fieldwork and only completed after leaving the field.

The diverse collection of data sets required a process of careful management in a variety of ways appropriate to each type of data. How the types were managed and analysed after leaving the field is outlined below. I gathered substantial amounts of data in various forms. In the end the increase in sample sizes meant using an exemplar methodology to limit the number of central participants. I chose an exemplar approach to present my findings from both central and staff participants.

Exemplar methodology

This research used purposive sampling, that is, approaching people with advanced dementia, or dementia with high care needs, to form relationship and then receive their consent and informed consent to participate (Taherdoost 2016). Due to the large number of people who became central participants, and the large amount of data generated, it was not possible to include every participant in the body of the thesis. Exemplar methodology provided a way of selecting from the original sample of central participants those people with whom I had spent regular ongoing occasions, and who exemplified the expression and enactment of voice “in a particularly intense… manner” (Bronk, King & Matsuba 2013, p. 1). I chose 12 exemplars from the overall sample of 24 central participants in the analysis chapters.

In the analysis and discussion chapters exemplars enabled a much clearer identification of diverse themes of the voice. In addition, exemplars highlighted social facilitators that inform and improve praxis (Bronk, King & Matsuba 2013). Representing these people as exemplars became the anchor points for these chapters, and indeed the entire thesis, by revealing the diverse manner in which people with advanced dementia convey their voices and engage in their lived experience (Bronk 2012). These people highlight how those with advanced dementia are able to communicate their lived experiences with insight according to their strengths.

The following table (Table 5) summarises the people who I chose as exemplar central participants and if they participated, their family member and their distribution across the 2 homes.

Table 5 Central Participants and Family Participants

	Central Participants: 12	**Family Participants 9**
Home 1	Luke	Son without Luke
	Lydia	Son with Lydia
	Philip	Wife with Philip
	Thomas	Daughter without Thomas
Home 2	Hannah	No family participant
	John	Wife with and without John
	Mary	No family participant
	Miriam	Daughter with Miriam
	Naomi	Husband with Naomi
	Paul	Wife with Paul
	Sarah	No family participant
	Timothy	Partner without Timothy

The twelve exemplar central participants

This compiled data set had five components.

- Transcriptions of audio-recordings (AT- Audio Transcript)
- Field notes in Participant Observation Diary (POD, Books 1 and 2) of one-to-one interactions and group activities
- The social-spiritual care plan for each person (RCP- Resident Social-Spiritual Care Plan)
- Field notes of personal artefacts of each person (RPA)
- My Reflexive Journal regarding encounters with each person (RJ- Reflexive Journal, Book 1 and Book 2). I included my thoughts, feelings, my resonance and my understanding of our relationship during the episode. I looked for ways others or I had affected the person, hindering or promoting their voice.

Each RSM had previously given permission to access the Home's computerised system of Progress Notes and Nursing Care Plans. However, I was unable to access these notes or the plans due to lack of the availability of a computer.

Choosing pseudonyms for the person and family members

Following confidentiality protocols, I carefully assigned a pseudonym to each person and their family member, to safeguard anonymity. I again realised the significance of one's name as several participants proudly told me theirs in full. I sought not to diminish or change the person's identity, but deliberated on another appropriate name. The eventual choice of pseudonym was written up in my reflexive journal, according to its meaning to me, my knowledge of, and relationship with each person over time.

The nine family participants

The compiled data of family members was comprised of:

- The semi-structured interviews with family members, in most cases with the presence and comments of the person, audio-recorded (RFI- Family Member with Resident Interview; FI- Family Member Interview).

The twenty-nine staff participants

The compiled data for the 29 staff participants came from 3 sources:

- Semi-structured interviews with staff members (SI- Staff Member Interview).
- Participant observations in one-to-one and group settings of participants (POD- Participant Observation Diary).
- Collection of organisational artefacts (OA).

Designating staff members

My field notes used staff members' roles as a generalised title to distinguish particular roles and responsibilities within the organisation, for example, 'carer', 'nurse', 'laundry person', or 'capability/ lifestyle coordinator' (see Glossary). Regarding specific staff members who became participants, I used a role title and pseudonym to differentiate between staff members holding the same role.

Transcribing the audio tapes

There were one hundred and nineteen audiotapes of conversations and interactions, as well as formal interviews with family and staff members to be transcribed. After each day of fieldwork, all of these recordings were downloaded onto a password protected laptop, then saved chronologically into separate folders designated by the person's name.

Due to my situated knowledge of their language and the challenges to comprehending this using only an audiotape, I personally transcribed every audiotaped recording with each person and all interviews with family members with the person. The transcription text included both the verbal language spoken, as well as the non-verbal language being displayed by the person that I indicated verbally during the recording. This monumental exercise amounted to five hundred pages of typed text in dialogue format. Two other transcribers who signed the confidentiality agreement were employed to transcribe the interviews with only family members, and with staff members.

Reading the transcripts

I then checked all the completed transcripts, reformatting them into paragraphs of interaction. The transcripts of each episode were compiled into one set of transcripts for each person. If the person's substitute decision maker was interviewed this transcription was included in this set.

The substitute decision maker for each person received their transcribed set, including my rationale for their pseudonyms, to read and sign off in their informed consent form. This research protocol understood the substitute decision maker's role as acting for their relative who was not able to do this. Subsequently each substitute decision maker gave their approval, in some cases, a few adding their comments about their surprise at the extent of their relative's participation, and my choice of appropriate pseudonym. Some family members expressed appreciation for the care with which I had engaged with their relative. All staff members interviewed received a transcript of their interview(s) to read and check before signing off on their informed consent form (see Appendix 15), as their agreement to the use of this transcript. Each transcript was returned to me, some with further explanations and examples.

Storing the data

In accordance with ethics protocols, field notes were in my possession throughout the duration of the fieldwork. The data generated for each participant reside in a file for each participant on my password protected and securely stored laptop. Data are securely stored electronically on this laptop and locked back-up drives, in my diaries and journals, and also on One Drive.

5.9 Analysing the Data

The process of analysis for each participant group is outlined below.

The twelve central participants

The ethnographer, Agar (2008) advocates

> *making talk the central source of data in informal work and pulling in other data to interact with it in a more dependent role (p. 109).*

Agar’s statement relates to my intention throughout this study. In seeking to be consistent with my ontology and approach to epistemology, the central source of data has been the voices of the people central to the study. I chose to take an approach contrary to that of the majority of research studies in the integrative literature review (see Chapter 3), wherein people with advanced dementia did not have direct input. In this study the developing of relationship with each person and gaining some knowledge of their personal characteristics guided a growing awareness of their voice repertoire. I adapted the ethnographic methods of interviewing and participant observation to take account of their repertoire to ensure the inclusion of each person’s voice and their ability to participate. These episodes became the data to be analysed, rather than foregrounding other methods. Therefore, in the analysis phase the compiled data set for each of the central participants, people with advanced dementia, was the predominant set to be analysed as representing their voices. All the additional data sets of interviews with family members and staff members, and my notes, have been used to give background, further describe and contribute to the representation of the voices of the people who were central participants.

Due to the diverse forms of the data of the central participants, and according to my bricolage approach, I chose to combine several analytical methods to:

- develop a specific thick description of each person’s voice;
- and compile these descriptions into an overall understanding of the voice of the person with advanced dementia.

The analytical framework: overall, detailed and stepped

There were several layers to the analysis process from a broad understanding of the person’s voice in relation to their profile and daily life. With this perspective I then moved to a detailed analysis of their voice characteristics using a stepped process as outlined below.

The overall framework for analysis was based on the following two analytical paradigms:

- The Voice-centred Relational Method (Gilligan et al. 2003), focusing on the facilitation of the person’s voice through relationships and interactions with others.
- The Narrative Performance Analysis (Riessman 2008) using a step-by-step procedure considering the person’s input as a narrative performed by them.

Combining both these analytical methods complemented both the relational context and the narrative form of this study. The authors of each method state that these can be used in conjunction with other methods. They describe their analytic process as leading to a development of themes and a greater understanding of the complex human phenomenon being studied (Gilligan et al. 2003; Riessman 2008). These two methods were integrated to provide the step-by-step process for analysis, as outlined below.

Two additional interpretive lenses provided more detailed analysis:

- Linguistic Analysis (Muller & Schrauf 2014; Schrauf & Iris 2014) identifies the verbal language and capabilities the person uses to interact with others.
- Dementia Care Mapping (DCM) (Brooker & Surr 2006; Mansah, Coulon & Brown 2008) uses a focused participant observation to identify non-verbal language and activities through the person's day (see Appendix 9 Observational Grid for Each Central Participant).

These two lenses took account of the person's voice repertoire having verbal and/or non-verbal components.

Each form of analysis contributed to the combined and detailed perspective of each person's voice. I now outline the step-by-step analysis process incorporating these four elements.

Stepped analysis process *(Gilligan et al. 2003; Riessman 2008)* (see Appendix 10 Table of Analysis for Each Central Participant)

Step 1: First and Second Readings and Hearings (on recorder) of central participants' data

By reading repeatedly, I familiarised myself with each person's transcript. Using this iterative process I ordered the sequence of interactions and observations, starting to synthesise the data.

Step 2: When', 'Where', 'Who' - Narrative Synopsis *(Gilligan et al. 2003; Riessman 2008)*

The data set was in lengthy texts of episodes of interactions in one-to-one and group settings in narrative form (Riessman 2008, p. 11). I labelled each episode with the essential details of the 'when', 'where', and the 'who', of those who participated, and their relationships to one another. I then developed an initial narrative synopsis of each person, inserting relevant portions of the conversation-interaction transcripts and my participant observations, gained during our encounters and developing relationship.

I identified the plot of each episode and the possible meaning(s) of the person's responses in performing their voice at that time (Gilligan et al. 2003, p. 160). I began to compile episodes with a similar plot into sections and apply subject headings. These headings were the genesis of themes.

Where I had interviewed their family member, or a staff member had made specific reference to the person, I included their insights with what were apparently relevant episodes in this synopsis.

Step 3: Analysis of layers of the person's voice in each episode *(Gilligan et al. 2003, p. 164)*

Step 3 (a): Linguistic Analysis *(Muller & Schrauf 2014; Schrauf & Iris 2014)*
In each episode I identified the minutiae of the verbal language forms used by the person, such as greetings, courtesies, formulaic language and extenders. I considered how co-construction occurred, for example, noting the initiating and turn-taking of the person and others or myself. I describe the person's expression of these verbal language forms in detail in Chapters 6 to 8.

Step 3 (b): Dementia Care Mapping *(Brooker & Surr 2006; Mansah, Coulon & Brown 2008)*
Using my adapted Dementia Care Mapping Observational Guide, I constructed a detailed account on an observational grid for each person of their non-verbal and accompanying verbal language, in their interactions and activities through their day (see Appendix 9 Observational Grid). I identify the person's enactments in detail in Chapters 6 to 8.

Step 4: Themes in the Narratives *(Gilligan et al. 2003; Riessman 2008)*
Through continuous analysis of the data of episodes, I refined the headings into themes for each person's enactment of their voice in the overall transcript and synopsis for each person. This process aided the tracing of interwoven themes previously identified in the research literature (see Chapter 3) such as agency and identity, and the consideration of new themes.

Step 5: Theological reflection and ethical reflexivity revisited
Finally, I reapplied the interpretive lenses of theological reflection and ethical reflexivity according to the principles outlined in Chapter 4. I focused in on relationships, the person's interactive capabilities and capacities, and the facilitative responses of others.

Step 6: Compilation of analysed data of central participants into themes
Under the thematic headings, I compiled extracts of episodes of central participants as exemplars of each theme. I present the thematic representation of this analytical synthesis for the central participants with a summarised analysis of each extract for each participant in Chapters 6 to 8.

The nine family participants

Family members contributed their input about how they facilitated their relative's enactment of their voice. In telling their relatives' story, past and present, the family member provided their long-term perspective. These insights were free-flowing narratives, later inserted into the text of analysis at places considered relevant to further inform the extracts of their relative.

The twenty-nine staff participants

Thematic analysis, outlined below, was used for the data set of staff participants. This analysis concentrated on content expressed verbally, and/or written. A theme refers to 'a specific pattern of *meaning found in the data set' (Joffe 2012, p. 209).*

Process of thematic analysis of staff data (Joffe 2012; Thorne 2016)

Step 1: I became familiar with the data set: identifying words, phrases, contrasts, and meaning units (Thorne 2016, p. 157).

Step 2: Through initial groupings, I chose generic categories and applied themes which refined these according to those directly articulated and acted out by staff participants (Joffe 2012).

Step 3: I reviewed themes, checking if they worked in relation to the coded extracts in the staff data set, thus generating a thematic 'map' of the analysis.

Step 4: I produced the final analysis of specific themes with selected extracts from the interviews and observations. These themes were informed by the final data set of organisational artefacts. For example, selections of text located in organisation newsletters enabled a clearer understanding of the organisational ethos statements (OA- Organisational Artefact).

The following table summarises details of the staff members who were research participants.

Table 6 Staff Participants

Home 1 - 12	**Home 2 - 17**
Residential Services Manager A, Ruth (RSM) Carers Annabelle; Bindy Cleaner - Valerie Chaplain - Patrick Hairdresser - Deb Housekeeping Manager - Elise Laundry Person - Kristie Lifestyle Coordinator - Prue Lifestyle Assistants - Adrianne; Bonnie Nurse - Aggie	Residential Services Manager B, Sue (RSM) Capability Coordinator - Serina Capability Assistant, - Joylene Carers – Ca; Deidre; Mercy; Roy; Briony; Nerida; Lisa; Carol Chaplain - Sharon Cleaner - Clare Nurses – Martha; Jade Volunteers – Clive; Pam

5.10 Writing up findings

In remaining consistent with the methods and conclusions of the analysis I chose a thematically based structure as the most appropriate way to present the findings. This arrangement highlights the contributions of the exemplar central participants in representative extracts of their participation with their friends, family and staff members, and myself, and further reflections from my field notes and research journal entries.

5.11 Conclusion

This chapter has described in detail the fieldwork phase and has outlined the practical and chronological details of the methodology (see Chapter 4). In describing the careful deliberations, decisions and actions, I have sought to depict my ethical reflexivity throughout this phase. I recognise how vulnerable and yet interdependent each of us have been in this unique, spiritual and emotional setting where people live, move and work together in community. I am aware that, achieving the delicate balance between ‘immersion’ and ‘objective distance’ is almost impossible in this situated and complex lived experience. In this study my personal positioning, attentive attitude and deep involvement have intertwined with methods of participation and observation. This research has been embedded in methodological underpinnings which have presumed the potential for relationships, as well as interactive opportunities and occasions with each person. As stated in Chapter 4 this methodological approach is grounded in a consistent epistemology within relationships of acceptance and inclusion, appreciation and participation, founded on a compassionate and just ontology.

Relationships between people with advanced dementia, others and myself are a fundamental feature of this study and a substantial aspect of the data. Early in Chapter 6 I introduce the reader to each of the 12 exemplar central participants by presenting a profile of each person. The formation of relationships and what transpired between participants and myself as the researcher, were interconnected realities and became the co-constructed data. Gardner (2011) affirms that in relationships our preconceived social constructions may be challenged and changed by experiencing the capacities and resources within another person. Chapters 6 to 8 elaborate on these data through the representation of extracts, exploring the findings regarding the voices of people with advanced dementia as they expressed and/or enacted their lived experience.

CHAPTER 6 VOICE IN FORMING RELATIONSHIP

Introduction

Chapters 6 to 8 focus on data analysis and findings. These chapters address the research questions: What are the ways the older person with advanced dementia expresses or enacts their voice? What enables older people’s voices in residential aged care?

I present the findings over three chapters, akin to three acts in a play with the unfolding plot reaching its climax in the final chapter. These chapters portray how, through numerous encounters over time we (people and I) formed relationships with each other, and how these relationships developed and deepened. I describe how people with advanced dementia adopted a daily pattern expressing their voices, often with strength, ability and capacity, despite experiencing challenges and changes in their lives. There is a sense of the person becoming in many encounters: becoming engaged; becoming stimulated to take initiative; becoming connected; becoming expressive of appreciating shared time together; and becoming across time as our relationship developed and deepened. The person occupies centre stage as they perform their storied-life in their verbal and non-verbal narrative with an attentive, appreciative and responsive audience or “communication partner” (Ellis & Astell 2017).

The concepts drawn from the contextual literature review, personhood, interdependence and citizenship of older people (Chapter 2), previous research literature (Chapter 3), and my methodological notions drawn from my theological reflection, ethical reflexivity and ethnography (Chapter 4), have informed my analysis and findings.

Each of the Chapters 6 to 8 present in thematic sections the findings of my analysis, drawing from the ‘combined’ methods outlined in Chapter 5. In each section I provide extracts of interactions, conversations, group activities and observations with each person, as exemplars to demonstrate the particular theme. The extracts seek to convey a sense of the immediacy, relational, interactive and performative aspects of the encounter with each person. The extracts are accompanied by contextual details, my interpretation of the person’s lived experience at the time, and my reflexive analysis to convey the meaning of the extract in answering the research questions. (Please refer to Front Pages: Definitions of Staff Terms and Roles; Glossary of Abbreviations Ch 5 [Methods] and Chapters 6 to 8 [Data Analysis, p. xiv]). The extracts of one to one and group interactions show how people’s voices were situated in their relational and social context.

This present chapter shows how people with advanced dementia enacted their voices in my forming of relationships with them. I approached these relationships with care and sensitivity, seeking to develop familiarity, rapport, trust and openness. Awareness of the “embodied and spatial context” considers the people who inhabit the different places, and how and for what purpose (Coffey 1999, p. 59). Through my positioning and reflexivity (see Chapter 4), I maintain a relational and empathic approach, aiming to balance this with researcher etiquette and boundaries (Luff et al. 2015). In five sections, this chapter shows how the person expressed their voice as relationships first formed. My analysis of data resulted in the following themes: 6.1 'Profile of Each Person': provides insights regarding each person from a variety of sources as well as my perceptions in getting to know each person. 6.2 'Voice Characteristics in Initial Contact', describes how several people and I first met, and the characteristics of voice they used. 6.3 'Voicing Response in forming Relationship', illustrates the person's voice response to our first encounter. 6.4 'Recognising Voice Repertoire', considers specifically how each person expressed and/or enacted their voice. 6.5 'Insights of Staff in promoting the Person's Voice', demonstrates staff's value of the person's voice and the ways they promoted and supported their voice.

Coming to know and appreciate each person holistically in our relationship was a most significant part of this research journey, and so I begin by introducing each person to the reader.

6.1 Profile of Each Person

The following profiles were compiled from time spent with each person listening to their stories, my noted observations (Appendix 9 Observational Grid), my choice of pseudonym notes and synopsis of the person's demonstrations of their identity, agency and storied-life, information gleaned from their "social-spiritual care plan", and the specific input of family and staff. Each of these profiles begins with the person's age and length of time in the aged care home. These profiles describe how each person with whom I formed a relationship expressed and/or enacted their voice repertoire according to their predominantly non-verbal, or verbal language, or blend of both, and their personal characteristics. The profiles are organised in alphabetical order according to each person's pseudonym. There are six women and six men, and the small cameos honour their contribution to this study and inform data analysis.

Hannah (90, 2 years) prefers to sit in her room through the day and come out to be with others for meals. Hannah has lived in the home for two years. She has two sons, grandchildren and great grandchildren who live on the other side of the city. One son and grandson visit some weekends and take Hannah out on drives. Born in the western suburbs of Adelaide, Hannah had five siblings. They lived through World War II and she still finds these memories traumatic. When Hannah met her future husband, they enjoyed going dancing. She was an office worker before the birth of their three children, then worked in the home, caring for her family. Their daughter died very young and Hannah continues to grieve her loss. After her husband's death, Hannah moved into the aged care home. Hannah has Christian faith and values the chaplain's visits and going to church services and music activities each week. During group activities Hannah watches and listens to others, holding her teddy close. She engages in the activity and responds if someone relates with her. Hannah enjoys reading and goes to the home’s library with a volunteer to borrow books. She says she is happy “on [her] own”, surrounded by her animals and special teddy. But she also likes to “sit and chat to someone in [her] room”. I consider Hannah has a quiet thoughtful personality, shown in the ways she chooses to spend her days and how she interacts with most others. She is able to speak with words and brief sentences, mostly in one-to-one situations in response to another’s attention, question and comments, and often only makes the sound “uhum” in response. She initiates comments about people and possessions important to her, and shares positive relationships with several carers and cleaners. Hannah has developed a “miaow” language with Cleaner Clare as their special way of interacting. Sometimes Hannah articulates her inner emotional experience in her words and speech tone. Hannah uses very few non-verbal and facial gestures.

John (85, 3½ years) spends his days sitting with his mates at the dining table, or with his friend Felicity, and with his wife and son, who regularly visit John. His wife is also a volunteer in the house where John lives. John spent most of his childhood boarding away from home in Adelaide because his father was a jockey overseas. He left school early to become a jockey and train horses. John performed in rodeos and was a remote outback station-hand working with his second wife, Frances for many years. John has enjoyed coaching his son and his rugby team. He mentored many teenage boys who came from difficult backgrounds. John is still held in high regard by them, now men in their fifties. His storied-life is a testimony to his thoughtfulness and care of others. When John first came into the home he took time to settle, and kept to himself. With the support of his family and staff John has settled in this as his “home” now. John’s responses still indicate he is a determined and independent person. Staff and his wife say that at times John still reacts with negative embodied language, such as grunts, loud noises or refusals, when he is feeling down, uncomfortable, or coerced by another person. Yet John is also a sensitive caring man who is aware of others’ reactions and concerns and endeavours to support them. I observe him going up to other residents or staff he knows and patting them on their leg or arm. John reaches out to his wife with a kiss and hug when she arrives. John now displays his embodied language in single gestures, a nod of affirmation or a look. He hums when he is content, while sitting with others, moving about or watering the garden.

Luke (91, 2½ years) likes to go for long walks around the home through the day. In his greeting and chatting with different people he meets along the way Luke demonstrates extensive verbal language, using sentences and long commentaries. He usually assists staff with laying the table and then sits in public areas with “friends”, enjoying their company. Luke has three adult children and is a grandfather and great grandfather. His family regularly visit and spend lengthy times with him each week. Luke grew up in Adelaide, studied at university and worked as a leader in the church and community support services, providing counselling and assistance to people in need. Later he and his second wife lived on a bush property and enjoyed bush walking. Luke likes to socialise with others one-to-one, with many hot drinks and biscuits through his day, and in groups.

He attends some of the group activities including bowls, the late afternoon group, and the weekly church service. Luke mostly displays a cheerfulness and sense of humour with his wry smile and quick puns, along with affirming the contributions of others. He has close relationships with several staff who appreciate his caring nature. Luke seeks to have a good relationship with everyone he meets through his day. He experiences frustration and sadness when this does not happen. Luke also becomes frustrated if he does not relate with, understand, or hear someone due to his hearing loss. When he is distressed Luke enacts agitated movements accompanying his verbal comments. He watches and takes his cues from others, intuits the meaning of their non-verbal gestures and takes turns in social interactions.

Lydia (88, 3½ years) usually sits in the lounge-dining room each day, often sitting forward in her comfort chair, listening for others and seeking their company. Lydia's eye-sight is limited yet her hearing is acutely attentive. She came into the home after her husband died. Her son and daughter-in-law live locally and visit several times a week. One daughter lives interstate and another overseas. They each visit as often as they are able, at least annually. In her homeland Lydia had been a seamstress, creating garments for the rich and famous before emigrating to Adelaide where she worked as a seamstress for a department store. Lydia married her husband who had also emigrated. They became leaders in their ethnic community, providing support and hospitality to their people when they arrived as refugees from their homeland. Their extended refugee "family" had often lived with Lydia and her husband. She has several adult grandchildren whom she had cared for as children. Lydia is a devout Christian, expressed in special icons in her room, attending the church service each week, and valuing the visits of her priest. She looks to relate to others as she had done throughout her life. Lydia has extensive words, sentences and conversation ability, expressing her reflective thoughts and asking questions of the other. She has the desire and capacity, when not tired, to sustain lengthy conversations on topic, including reminiscing about her homeland. Lydia continues to display her cultural and social conventions and courtesies, having lived her life providing service and hospitality to others. Sometimes Lydia expresses her hospitality with her words and gestures, by offering her morning tea to others. She only likes to attend activities nearby her room because she becomes anxious in unfamiliar places. When staff interact with her, Lydia settles and tells them stories of her life in her homeland.

Mary (92, 4½ years) prefers to sit on her own in her room when she needs solitude, and then comes and sits at the dining table, occasionally chatting with her friend Sarah. When she comes to the dining room she seems content to sit quietly watching others. Mary grew up in England and experienced many traumas in her life and as a result sometimes is distressed. She lost her father and brother in World War II. Mary had worked as a receptionist. She is divorced and has three adult children and a sister who visits occasionally. Mary finds these relationships difficult. Sometimes she appears agitated, and her words and facial gestures are negative and even harsh about herself and in response to others. At times Mary will only respond positively to certain staff who she knows well and trusts. Some carers will come alongside to support and calm her. Mary appreciates living in the home because she has certain staff “friends” who are “family” to her, giving her support, comfort and cheering her up. She knows lots of songs and poems by heart and may recite an appropriate ditty when she is amongst others. When a situation triggers a good memory Mary may reminisce. She remembers being in a choir at her church school and singing the hymns. Mary likes to come to the church service in the home because she likes to sing the hymns. Mary seems to have a feisty and resilient personality at times, perhaps borne of her hardships through her life. But also, she is prone to times of great sadness, reacting to continuing great disappointment in relationships with her family. When Mary is calm within, she smiles and makes apt and incisive comments, poking fun with her quick sense of humour.

Miriam (89, nearly 2 years) usually sits on her own with her doll baby or animated dog and observes people coming and going. She states her opinions about others and situations she notices in proximity to herself. She calls out to whom she chooses to gain their attention. Miriam expresses disdain in her facial expressions, accompanied by words if she considers something is not up to her expectations in cleanliness or appearance, or if someone ignores her. Miriam’s daughter and son regularly visit with their partners, and take her for drives and to their home. She enjoys having a chat with staff, especially the chaplain and carers in her house, and her visitors. Her husband also lived in the home until he died. Miriam and her husband met at a dance and continued to enjoy dances at local country halls. They lived on a vineyard property working the land for many years. Carers used to ensure they spent times together, including setting up candlelit dinners for them. Miriam enjoys listening, singing to, and dancing with music, and attends any activities with music, including church services. She seeks reassurance and affirmation from staff she knows, and likes to be noticed and affirmed by them. At times Miriam will call out repeatedly, “Who am I?” She seems to become calm when a carer responds, “You are Miriam, and you are beautiful”, to which she nods and says, “Yes”. When not being noticed by staff Miriam can become downcast. She likes looking through women’s magazines and having a regular hair appointment with the home’s hairdresser who pampers her, and her nails painted. Miriam happily then displays herself to staff and receives compliments.

Naomi (84, 4 years) often sits in the dining room facing towards the entrance watching staff coming and going and interacting with them. Naomi’s husband visits most days and their two adult children and grandchildren come weekly. She was from an affluent family and grew up with maids. However, she has preferred the simple life, leaving her childhood home in her teenage years and working away and overseas until she married Beau. They have celebrated 63 years of marriage. Her husband and two children and their friends enjoyed holidaying in the local coastal area and eventually lived at the beach in their retirement. Naomi authored an autobiography of their life as long time, well-known local residents. She continues to initiate and enjoy engaging in conversation and relationships with staff. She is usually an enthusiastic, effervescent person with people she knows well, and reaches out to them for company. Naomi also expresses effusive gestures and words to welcome staff, other residents and families as they come into the room or walk nearby. She notices and responds with words like, “You’re gorgeous,” when others acknowledge her with respect, gentleness and kindness. In her non-verbal language and words Naomi expresses appreciation of the care of staff. However, there are times when Naomi is sad, apparently when she feels alone, overlooked or needs company and someone to chat with. She displays acute observational ability when looking for another’s company, by calling out using smiles and bodily gestures. Naomi reaches out her hand and positions her body towards them when they come near. She expresses her emotional and appreciative words with facial expressions, raising her eyebrows and eyes opening wide, looking directly into the eyes of someone who is familiar and/or attentive. She echoes the other’s words and sounds over and over. Sometimes Naomi will make a profound and meaningful comment of affirmation to the other person.

Paul (81, 1½ years) wants to be positioned each day looking out of the window towards the horizon, which he vividly describes verbally and with gestures as the sea. When the trees beyond the window move vigorously with the wind, Paul points to what he sees and comments about the ships coming in as he has during his working life. Paul often uses words and loud sounds and effusive non-verbal bodily and facial gestures to describe what he experiences, indicating concern or calm and pleasure about the weather and the tides. His wife, Bernice, says that they have a long and happy marriage. She visits each day “so Paul keeps telling his stories”. They have three sons, two of whom are in the navy, and a daughter, who all visit regularly. Paul’s father and grandfather were trawler skippers, and he used to be in the navy as a sea captain. Later when they emigrated as a family to Adelaide Paul became a pilot docking the ships. Paul’s motto is “Life is what you make it, isn’t it?” He is able to follow Bernice’s words and enact his opinions and choices with authoritative gestures, words and tone of speech. He concisely corrects Bernice when he considers she has made a wrong assumption or talked over him. He kisses his wife when she comes and enacts turn-taking in conversations, ensuring that he gets a turn as part of his courteous rituals.   Paul’s social-spiritual care plan states, “Paul is tactile”, and he likes looking at shipping magazines and keeping busy with his hands, “rolling up the ropes” while socialising with others. He attends the Men’s Group and has a laugh and a beer with his mates. Paul can become distressed and agitated by inactivity or when his agency and authority are overlooked. Mostly Paul appears a courteous and dignified man and responds positively to respect and courtesy. When another acknowledges his comments, Paul nods with assurance.

Philip (92, a few months) seems to need his times of solitude when he goes for a walk around the home. But often he is looking for the company of others. Philip came into the home in traumatic circumstances, having suffered an illness, being in hospital and his wife, Phoebe, also being ill. He still looks for Phoebe each late afternoon. His wife and five adult children regularly visit and bring memorabilia and photos to converse with him. Philip has always been a loving, supportive husband

and father, getting involved in coaching his children’s sports as they grew up. He spent his childhood in a large country town and then went to Adelaide to complete his schooling. After leaving school Philip returned to the country, becoming a hurdles jockey before a serious accident. This led to a career change into the Electricity Department and working in rural and remote locations. Philip served in the army, and spent his adult years as a significant local community leader and justice of the peace. During the day Philip continues to enjoy socialising, especially sitting quietly listening to others one-to-one and participating in small groups. His words and sentences are not always clear, but he is able to sustain lengthy conversation with someone familiar and responsive to him. He seems to form a point of view, including a critique of staff and their practices, which he will then state to someone who is familiar and attentive. He uses words and sentences thoughtfully and, at times avidly and enthusiastically, along with his apt bodily and facial expressions. Philip sits each day with his friend Luke at the entrance, watching people coming and going and greeting them each time. He continues to display his kind, generous and appreciative nature towards others, with courtesy and care, often doing useful activities to assist others like sweeping, which he did in his own home. As he explains, “It’s nice to say the nice”**.** Philip values being welcomed and supported by others, responding cheerfully. Staff also respond to Philip’s courtesies and friendliness, greeting him enthusiastically.

Sarah (91, 6 months) grew up in a country town and never went to the city until she married and then lived in Adelaide. As an only child Sarah had a very close relationship with her cousin, even when she moved interstate later in life. Sarah is widowed and has two daughters and a son who regularly visit her in the home. Her grandchildren and great grandchildren visit during the school holidays. Sarah was a long-time volunteer in local aged care homes, chatting with the residents. She continues to sit at the dining table during meals and refreshments for lengthy times of interacting, particularly with her two friends and certain carers who stop to chat. She appreciates talking with the chaplain. She continues to enjoy chatting with staff and interjects if they overlook her, talking with one another at the kitchen servery. As we form a relationship Sarah displays her growing ease with me in her social courtesies, humorous facial expressions and apt sayings, as I note she does with others. Sarah often has a smile on her face and expresses her sense of humour, grinning delightedly when she cracks a joke. She enjoys propelling herself in her wheelchair with her feet around the house, never stopping for long. In this phase of her life Sarah’s memories have returned to her life in her original home town and she grieves the loss of her life there. She still describes the town in lengthy and vivid detail with great sadness. As she reminisces she states, “As a memory that wasn’t”. Sarah grimaces when she is struggling with her grief. As part of her memories, if Sarah sees a dog she immediately puts her fingers in her mouth to whistle it up. Sarah always loves having her hair done at the home’s hairdresser and then appreciates the compliments of staff afterwards.

Thomas (89, 1½ years) mostly spends his days on his own, moving between his own room and his art place. The earlier death of his wife was a major tragedy and he continues grieving her loss. With bodily gestures and facial expressions, words and sighing, Thomas enacts his grief. With a love of ballroom dancing, Thomas met his wife at a local dance. Devoted to each other, they had few friends and were married 62 years. His daughter lives locally and visits each week. His other daughter lives overseas. Thomas grew up in England, and at an early age showed great prowess in painting, crafts and writing and won major competitions as a teenager and adult. He also achieved wins as a competitive swimmer. Thomas was deployed in the military police in the Middle East and wrote every day to his wife and family. He then worked in tool making at the Ford Motor Company in England. As a family they emigrated from the United Kingdom to Adelaide. Thomas then worked with Chrysler, advancing eventually to quality control manager before retiring. He attended Freemasons but was mostly at home with his wife. As a singer and lover of music Thomas enjoys all music activities in the home. He feels most comfortable chatting with women and visits the home's RSM in the late afternoon for a chat. Sometimes Thomas repeats lengthy stories of his courage and accomplishments when lifestyle staff sit and listen, and he does this with me on a number of occasions. According to his daughter Thomas has always been competitive with men. He raises his fist to demonstrate protecting his territory and becomes aggressive in his verbal language, and no one would want to cross him. Thomas continues to be an artist and becomes engrossed in his art in the art place set up for him, preferring his solitude.

Timothy (58, 6 months) interacts only with people who are familiar to him and with whom he has a relationship. He and his partner, Charis, have been together twenty-six years, and had previously enjoyed travelling together. They used to lived interstate before moving back to South Australia where Timothy had grown up. Charis lives locally and visits regularly through the week, especially coming during lunchtime to assist Timothy with his meal. They are very close, do not have children and have only a few local friends and family. Timothy was a fitter and turner and maintenance man in industrial work. He had enjoyed photography, fixing things, and playing his guitar, especially the music of the sixties. In the home Timothy and his partner spend special times sharing their love of nature, their football teams, and looking at photographs of family and their extensive travels together. Timothy particularly responds to his favourite music, Pink Floyd and the Beatles. Timothy's responses are predominantly non-verbal, enacting these clearly without words. He is very expressive with his eye movements and gaze when he is observant of people who are familiar, especially staff he knows, and also what is happening around him. Interaction with Timothy may gradually emerge through being together and interacting. Occasionally Timothy recognises a question from someone he knows and he uses brief words and/or sounds in response. He takes note of the affirming responses of someone he knows, repeating his actions non-verbally, for example, continuing to play the hand-held music machine. He disengages from someone he does not know. Timothy continues to seem to be a quiet thoughtful man, calmly responding to others he has got to know who interact with him during the quiet table activities, or during lunchtime in the dining room. When he hears his favourite song, “Close your eyes” by the Beatles, Timothy sings along to a few lines with his perfectly pitched deep vocals.

These profiles of central participants show how each person in this study had their unique way of enacting their voice. I have named their unique voice language their particular ‘voice repertoire’, in their communication abilities and personal characteristics, and will define this further in Chapter 6 and continue to describe each person’s voice repertoire through Chapters 6 to 8. In each profile I have described the predominant voice abilities I witnessed each person use to communicate. Some people expressed themselves in their ability to find and express words, including in sentences, asking questions and reflective comments. Many people conveyed their voice repertoire in their expression of spoken words, singly, in phrases, and/or in sentences with displays of facial gestures and bodily movements seeming to synchronise with the voicing of their verbal language. For several people, their predominant voice repertoire was enacted in bodily gestures and facial expressions, indicating their thoughts, feelings and responses. While noting these people used mainly non-verbal communication, I also observed that they might still use their speaking capacity occasionally in a single word, phrase or saying in response to others. Each person was also able to accompany their ability in voice communication with their personal characteristics, demonstrating their voicing of aspects of their agency, identity and storied-life.

6.2 Voice Characteristics in Initial Contact

This theme relates to how the person demonstrated their preferences and choices in the very forming of my relationship with them. People used a range of ways to communicate during these early encounters, sometimes non-verbally with gestures, and sometimes using words as described in the sections below. Two key aspects were identified in the data- those of taking initiative, and performing social conventions.

Taking initiative

A sub-theme is how a person enacts their voice characteristic by taking initiative for a particular purpose. I observed Hannah, for example, initiate her voice to point out to me the importance to her of her possessions.

Hannah - showing what is important

Hannah is sitting in her room when I knock, and my field notes describe our first encounter:

> *Hannah immediately nods to the line of cuddly animals on her bed saying, “They are special”. Placing her teddy on her chest, she states, “I love him.” Thus, Hannah expresses how much they mean to her. While I am surprised by Hannah sharing this intimate detail so early, it seems her animals are foremost in her life. In this*

> *initial visit I learn that Hannah comments and responds quietly and gently and I mirror her way of being. She has some verbal ability and appears most comfortable referring to her valued items, as she points to her knitting and books, with few words. As I say good-bye Hannah says, "Nice that you came", appreciating my visit and saying "That would be OK," to my request to return.*
>
> *Extract 6.1 (POD, Book 2, Home 2, 25/06/2018).*

Hannah takes the initiative in directing my attention to the various possessions in her room, especially her arranged animal companions. In acknowledging and affirming what is utmost for Hannah I express my respect and interest, and seek to begin to build a connection with her. During field visits I call in regularly, becoming familiar with Hannah who smiles and greets me. I observe Hannah chooses mostly to sit in her room with her companions, especially her teddy who always sits with her. Our repeated pattern of interaction indicates that simply being together gives Hannah the opportunity to voice what is important to her, and to be responded to and acknowledged.

Miriam - initiating conversation

Similarly, Miriam initiates conversation about her baby doll as I walk towards her the first time:

> *Miriam: Don't know the clothes she's got today. She looks like it... Julie: Can I sit with you? Miriam:…Yes, that's alright. She loves me. Julie: Oh, does she? Miriam (assuredly): I think so. Julie:…You're taking special care of her. Miriam: I love her too. Julie: My name's Julie anyway. Miriam (firmly): Julie, oh alright, well I'm Miriam. Julie: Hello, Miriam, very pleased to meet you. I'm a student from university. Miriam: Oh, are you! Miriam (looking at her baby doll): You only got to look at it to tell. Julie: No, she doesn't look too well. And you would notice that. Miriam: Yes, I would! I'm a bit fussy like that. Julie: Good on you being fussy, Miriam. She needs your love and care. Miriam: I think so. She does. Julie: She needs some clean clothes. Miriam: You're right there. No, that's not me. Julie: No, you're thorough? Miriam: Yes, I am.*
>
> *Extract 6.2 (AT, RI, Home 2, DRm, Miriam, 3/07/2018).*

In this interaction Miriam makes definitive statements to draw my attention to her doll baby's appearance. She exclaims, "I'm a bit fussy…that's not me", expressing her insight about who she is and is not, and seeming to link her agency and identity to this concern. I affirm Miriam in her self-assessment as a way of encouraging her to express her voice. In our first encounter, through Miriam taking initiative, I learn some of her voice characteristics and aspects of her life which are important to her. Miriam seeks to be acknowledged and responded to, and reacts positively to this. She actively seeks others' attention to realise her care in looking after her baby doll's appearance.

Timothy - enacting non-engagement

Each person demonstrated their wishes regarding my initial introduction. Several people appear reticent as was the case with Timothy and his initial lack of response to me:

> *When I first see Timothy, he is assisted by two carers in walking to the dining table for breakfast. After he is seated and appears settled, I approach and introduce myself. However, he does not respond. Appearing still sleepy, he looks at me then looks away. So, I leave him, approaching him later after his breakfast. He looks more alert and I again introduce myself. Timothy looks at me briefly, again not engaging with me. Instead, he sits still, looking at others around the table, and the carers at the servery.*
>
> *Extract 6.3 (POD, Book 2, Timothy, 29/06/2018).*

This extract demonstrates Timothy's silent, yet clear non-verbal voicing of non-recognition of me in his fast eye movements towards me, and then turning his face away perhaps to avoid eye contact with me. I consider Timothy's response to be his taking initiative to not connect with me. Having not met me I recognise I am unfamiliar, unlike other people and staff who Timothy spends his day with. In this first encounter I notice that Timothy's attention remains on those he knows. Afterwards I seek to gradually become familiar, greeting Timothy cheerfully, and sometimes sitting quietly with him and others during refreshments and lunch. I am attentive to his voice enacted in his eyes, facial movements and gestures, being respectful each time to not make him uncomfortable.

Lydia - drawing attention to her needs

Lydia in contrast, uses her spoken voice to call out when she needs others to pay attention to her needs. Field notes detail my first meeting with Lydia:

> *Before I meet Lydia, I hear her calling out and sounding agitated. As I arrive another person says, "Help Lydia". I sit beside her in her comfort chair (see Definitions of Staff Roles and Terms) and gently introduce myself. I feel the sun's heat through the window. Lydia is moving her body and feels hot. Unable to use her call button she calls out to gain attention. I find a carer who comes to make Lydia comfortable.*
>
> *Extract 6.4 (POD, Book 1, Home 1, DRm, Lydia, 6/11/2017).*

Lydia uses her speaking voice instinctively as part of her. She demonstrates her ability to call out in words. These words, not relaxed, sound strong to me and determined to get attention. With no staff member nearby responding, Lydia's expression of need prompts her friend and I to relay this to staff further away. I acknowledge the other person for their assistance. A carer hears and comes promptly alongside Lydia to ask about, observe and respond to her needs. Despite constantly refocusing from one person to the next I observe several staff appearing calm, caring and centred on their arrival to care for the person, as this carer does in responding to Lydia’s needs.

My observations of people taking initiative to interact in our first encounter were varied. Both Hannah and Miriam enacted their intact ability verbally and with gestures to draw attention to what is important to each of them. Timothy on the other hand, initiated disengagement from me, shown non-verbally. Lydia called out for attention with clear words for assistance to whoever would hear. I was attentive to being respectful and mirroring each person’s initiative in my responses, to recognise their personhood, and begin to build our connection.

Performing social conventions, courtesies and sayings

This sub-theme relates to the observation that the person often continues to enact their voice in ways that are instinctive and/or habitual in their social interactions. These voice characteristics may include social conventions, courtesies and proverbial sayings, as described below.

Lydia - enacting social conventions

> *Her needs apparently having been met Lydia then calmly initiates conversation with her apt question, “Where do you come from?”, directly looking at me. I quietly respond, looking at her and stating it is good to be here and meet her. When Lydia appears tired, I begin to leave her and she responds, “That is alright”. I notice Lydia is soon asleep.*
>
> *Extract 6.5 (POD, Book 1, Home 1, DRm, Lydia, 6/11/2017).*

I notice that after Lydia settles she is able to initiate our conversation. She demonstrates her ability with the social convention of asking questions, apparently to get to know me. I reciprocate with short chunks of information about myself, not wanting to overwhelm her. As I reply, Lydia’s non-verbal language communicates concentration, with her eyes on me and nodding in response to my words. Lydia’s intact ability with various social conventions and courtesies maintains our interaction. I mirror her body language, asking Lydia similar questions as we begin to form a rapport and get to know each other. Eventually, as I notice Lydia tiring I prepare to take my leave by slowing my speech. She seems to notice this, and concludes our interaction with her courteous words, indicating she is ready for our parting.

Sarah - displaying courtesies

When I first encounter Sarah she is moving around in her wheelchair, using her feet as she chats with Carer Deidre preparing breakfast at the servery. Deidre indicates her breakfast is on the table:

> *Deidre: Sarah, do you want to come back to your porridge? Sarah: Where? Deidre: You’ve got your breakfast here, my lovely. Sarah: Where? Here?…Oh, thank you.*

> *Deidre: You’re welcome. Sarah: Alright thank you. Julie (hesitantly): Hello, Sarah… can I sit with you? Is that OK? Sarah: Beg your pardon? (abruptly) Julie: I’m sorry. Can I sit with you or not? Sarah: Well, why, who are you? Julie: I’m Julie, a research student here. Sarah: Oh, I see. Well, I don’t know. Well, OK. (Deidre laughs) Julie: No, I understand. You don’t know me! That’s a good point, Sarah. Sarah: Oh, that’s alright, dear. Julie: I just thought I’d say hello. Sarah: Oh, thank you. That’s nice. Deidre (to me): Would you like a cuppa?…*
>
> *Extract 6.6 (AT, RI, Home 2, DRm, Sarah, 18/06/2018).*

I note that Sarah queries my arrival in contrast to her relaxed interaction with Deidre. I then step back and enact a courteous introduction, allowing Sarah space to adjust to my presence. Sarah enacts her courtesies of appreciation and affirmation towards Deidre. When I exhibit these familiar courteous formalities, Sarah then expresses congeniality in her receptiveness towards my joining her. She includes me affirmatively:

> *Sarah: You’re very young. Julie: Oh, thank you. I’m actually a bit older than I…thank you. Sarah: I’m just a jumb (sic)…really. Julie:…are you? Sarah: It’s alright so far. I’m not that …I’m not into it much. Julie: Do you like just having a bit of quiet time? Sarah: It’s on…it just doesn’t come. Julie: Yeh, yeh. That’s nice and warm. Sarah: No, I’m not the best of it here. Deidre (quietly): Oh, Sarah. Julie (quietly): Just quiet and shy….A cuppa warms you up, doesn’t it Sarah? Sarah: Oh yeh, I quite like it…*
>
> *Extract 6.7 (AT, RI, Home 2, DRm, Sarah, 18/06/2018).*

Carer Deidre expresses her empathy for Sarah in stating that she struggles living here sometimes. As we sit together Sarah also indicates her insightfulness into changes she has noticed:

> *Sarah: Not lately. Not really. No. I don’t eat like I used to. Julie: Mmm. Mmmm. Sarah: I don’t do anything like I used to here. Julie: No. Mmm. Sarah: Some that I used to know. Julie: Oh, are you missing them? Sarah: Oh, of course. Julie: Oh, I’m sorry. Sarah: But you can’t do anything about it. Julie: No. Oh that must make you sad at times. I think we miss our friends when they go, don’t we? Sarah: Oh yes. Of course. A lot…Yes you lose a lot of things.*
>
> *Extract 6.8 (AT, RI, Home 2, DRm, Sarah, 18/06/2018).*

Sarah appears to appreciate having someone to sit and listen to her. She is aware and able to articulate changes in herself and in losing others since living in the aged care home. Sarah demonstrates her insight in articulating her ongoing emotions about her losses, expressed in her words and tone. She also displays her intact wisdom from her experience, in commenting that losses are unavoidable. I listen and express my empathy, responding with attentive sounds and eye contact, and responsive questions. Sarah seems to have said all she wishes to for now, and we sit sipping our drinks. I learn in this first encounter that Sarah appreciates engaging with others in a friendly and courteous manner, with sustained conversation and insights about her lived experience. Some of this experience is of loss and grief and appears painful for Sarah to recall. Subsequently, with Sarah's earliest prompting, I learn to courteously introduce myself and notice how she and each person wishes to relate to me at the time.

Paul - enacting respect and courtesy

Knowing the person, their personality traits and preferences is important for providing respectful and appropriate care. In my first encounter with Paul, Carer Nerida is placing him in his comfort chair according to Paul's preference. Paul looks at me as I tentatively approach them:

> *Nerida: There you are, Captain…(turning to me). We (staff) always position Paul so he can look out the window towards the sky. This enables him to relive his work experiences at sea. Julie: Hello. Can I sit with you? Paul (hand gesturing with raised eyes to indicate where I may sit): Tchoose (sic). Julie: Can I? (Looking at him to see it is alright to sit alongside him.) Thank you very much. Paul: Yes. Nerida: Paul was a Captain, Julie. Julie: A captain! Good morning, Captain. Paul: Oh, thank you. (He chuckles as he nods his head.)*
>
> *Extract 6.9 (AT, RI, Home 2, DRm, Paul, 29/06/2018).*

As she positions Paul to look out the window, Nerida courteously takes the time to introduce me to him and tells me a little about him so that I too can get to know him. In these thoughtful actions Nerida provides person and relationship-centred care to Paul. Nerida demonstrates her respect for Paul with his former title, "Captain". Paul immediately responds courteously to my greeting by indicating where I might sit. During our exchange, another carer passes saying, "Be careful," as he gestures Paul becoming aggressive. I am surprised by this, not taking note whether Paul registers this warning. I reflect afterwards how these two carers act in contrasting ways towards Paul. Consequently, I consider whether by their differing personalities and modes of relating, they might prompt Paul's different reactions to each of them. I observe the former carer relates considerately with Paul, positioning him carefully, and being respectful and courteous. I observe Paul responds to respectful care with his courtesy.

Philip - expressing proverbial sayings and social courtesies

When I meet Philip out walking, I introduce myself. He smiles and courteously doffs his hat with a slight bow, and I respond in-kind. I ask if I can visit him in his room and he cheerfully agrees. We look at Philip's photographs, one in his official regalia, depicting his life of care and service. In the next extract Philip explains a photo of a special event in his honour:

> *Philip: Oh yes,.. they took all the bodies differently…Everybody sort of put something on it…One of those days…comes up pitch… Everybody got in it too because they knew it was special for the day. It was a damn good time… Julie: What town was that? Philip: in the water and North Adelaide…I thought it was a special spot. Julie: You look very smart in your…robes. Philip: Yes, it came up well…Yes,…and the badges…Yes, my day for a long time…important long time too… Julie: Fancy getting a reserve named after you... Philip: That's priceless …You had good days while you're there. Julie: Looks like you had very special day... Philip: Yes, a lot of people took the right thing to say and it helped. Yeh it was good. Julie: That's for sure. Did you make a speech? Philip (reflective and enthusiastic): O yeh, I made a beach (sic) and start stampese (sic) and turning over the singlets (sic) and effective figurettes (sic) and the gaze (sic)…that was because so much game matter in the gases spread in big account with westorf and bega (sic)…just one of those things… Julie: one of those things… Philip: Special day, everybody's got a bit… Julie: Oh, that's good. You've got a great big smile on your face. Philip: Oh yes, that was good. Julie: That's lovely. Beautiful pictures of you. Philip: Yes, spoilt.*
>
> *Extract 6.10 (AT, RI, Home 1, ORm, Philip, 4/12/2017).*

Philip expresses with strong verbal and non-verbal gestures his appreciative memories of this special community event in his honour. Responding to my affirmations, Philip portrays himself with humility, reliving this occasion, using words, phrases, sayings and lengthy sentences. He uses several proverbial sayings like, "that's priceless". Our engagement with the photos prompts Philip to comment in response. I begin to gain a sense of Philip's values and commitment to his community in service. The display of Philip's personal possessions seems to testify to what is important to him, as a tacit and tactile representation of his storied-life. Looking at these possessions together seems to have encouraged Philip's positive reminiscence and built our rapport in this first encounter.

From the beginning I sought out Philip to spend time together, feeling an amiability and synchronicity between us. As we walked together and chatted about what Philip observed, he voiced his responsiveness to me. While at times being demonstrably friendly, Philip and I were respectful and courteous towards each other. I observed Philip expressing his voice in initiating interaction with me and others, displaying humility, amiability, courtesies, and especially his purpose of having companionship.

In sum, I found that social conventions, courtesies and sayings are characteristics of the person's voice, which they may use in initiating and interacting with others and in forming relationships. I encourage the person's responses with introductory comments about myself, questions and affirmations like, “Good to be here”, and gestures such as nodding and eye contact. Together we display ordinary reciprocal social conventions, gradually becoming more familiar with each other, building rapport and connection. Sarah demonstrated that she required the habitual conventions of courtesies in order to become relaxed and interactive. Philip used formulaic/proverbial sayings familiar to him, to interact more easily and keep the conversation rolling. Paul also enacted social courtesies in our initial encounter. Lydia showed her recognition of social conventions in drawing our encounter to a conclusion. I learn early-on that the person appreciates receiving signs of our encounter concluding so they can prepare to move on, as did Lydia.

6.3 Voicing Response in Forming Relationship

The second theme identified refers to the range of positive responses the person voices in the early formation of relationship. These positive responses include words or gestures of humour, appreciation, pleasure, contentment and calm, and/or the other, including myself, remaining with the person. These responses by the person appear to demonstrate the significance of the encounter to them, as shown in the following extracts.

Luke - sharing humour

Lifestyle assistant, Anthea, tells me that Luke is no longer able to participate in a larger interactive group. She asks if I will be with Luke during this time. I perceive a potential opportunity to become better acquainted with Luke. In this first encounter I join Luke in the ritual of tea drinking, knowing from staff that he enjoys this. As I sit calmly sipping tea, Luke appears to move from being agitated looking for Anthea, to becoming calm as he drinks, seeming to mirror my demeanour. Knowing from his social-spiritual care plan that Luke’s preference is often a walk, I suggest this and he agrees:

> *Luke: Alright. (He greets others and chats along the way.) How far are we going? Julie: How far do you want to go…around the corner? Are you getting tired? Luke (raised tone): No, I’m not getting tired. Julie: Oh good. Luke (strongly): I’m getting higher. Highered (as Luke stands up tall). Julie: Oh you are getting highered, standing up tall. Luke: Yeh, how’s that? (He winks at me with humour). Julie: Thanks for the wink, Luke (as I laugh).*
>
> *Extract 6.11 (AT, RI, Home 1, Passageway, Luke, 5/01/2018).*

Our walk becomes an opportunity for me to observe Luke taking initiative in setting our direction and pace, and interacting with others. He appears to become more relaxed as we walk. I quickly learn that Luke is cheerful with a sense of humour and adept with puns, as we look out the second story window. Luke’s humour suggests he has become more trusting of me, and is appreciating being together. I take my cues from him in his brief statements and bodily gestures, not outpacing his words, and mirroring his actions respectfully (OG- Luke). I write later about my feelings and how they moderate during this first occasion together:

> *In the beginning I sensed Luke's anxiety at times, feeling some anxiety myself, uncertain how he would respond to me. I briefly thought he might become frustrated with me, but he wasn't alarmed. Just got to know each other slowly, settling into his ways. I felt calm as we had a cuppa and then enjoyed being together, with Luke's humour rising to the fore. Retaining a calm and responsive presence with Luke seemed to have the effect of relaxing him and his becoming responsive light-heartedly. We shared an affable time.*
>
> *Extract 6.12 (RJ, Book 1, 5/01/2018).*

Becoming relaxed in this encounter I become more present to Luke, and attentive to his ways. Luke's humorous response to me is an intact personality trait. According to his son, Luke has always had a sense of humour, especially helpful in his interactions with others as Luke transitioned into dementia (AT, FI, Ch, Luke's Son, 9/03/2018). When I leave him, Luke cheerfully says, "Thanks for coming", expressing his appreciation for the time we have enjoyed together (POD, Book 1, 5/01/2018).

Naomi - displaying appreciation

I observe that many people enjoy the company of others, responding to expressions of kindness, care and relationship by voicing their appreciation. Naomi initially responds with her appreciative words and gestures towards me as I sit beside her in our first encounter.

Naomi is by herself in the dining room. As I arrive she sees me and sits upright in her comfort chair. Our eyes meet and we smile as I go up to her:

> *Julie: My name's Julie. Naomi: Yeh. Julie: Yeh, yeh. And you've got a beautiful smile. Naomi: Yes… Julie: Yeh! Naomi: Ooooh! (expressively) Julie: Yeh! Naomi: Yea! Julie: Yea, that's right! Naomi (exclaiming): Good Lord! Julie: That's amazing!… Naomi: And what do we sell? Julie: Mmmm… I wonder if you've had breakfast yet? Naomi: ninety none…I didn't know. Wonder, wonder… Julie: Wonder, yes true… Naomi: And when did he do… Julie: Yep… Naomi: Gor. Julie: Amazing. Naomi: God, what we he? Julie: Do? That's a good question. Naomi: Yes, whater (sic)… I don't know what we could do with it. Julie: No, you don't? Naomi: No (definitely) no when the words called life (very expressive in a low tone)… (We sit quietly as Naomi with a concerned facial expression notices John falling and staff arriving to assist him.) That's a grabber (holding my hand tightly in concern)… Julie: Sometimes good to sit quietly isn't it? Naomi (brightly): Lovely time. Oh, you're*

> *gorgeous, gorgeous, gorgeous… Julie: Oh, thank you. So, I put my hand on yours and you give me a big smile…It's lovely to meet you, Naomi. Naomi: Yeh… Julie: Thank you. Naomi: Thank you! (most affirming tone). Thankyou… Julie: It's good sitting with you… Naomi: Yes! Yes! Yes! Naomi looks across the room, noticing John is falling and she expresses concern. She holds my hand tightly as John is assisted by a carer..*
>
> *Extract 6.13 (AT, RI, Home 2, DRm, Naomi, 29/06/2018).*

Naomi's visual acuity and awareness are sharp as she sees me coming and responds warmly to me. She has much to say, with words and hands reaching out with effusive gestures, encouraging my response. Her question to me, "What do you sell?" demonstrating her word finding is challenged, yet seems apt, asking why I am here. I mirror Naomi's tone in her apparent pondering. Naomi also follows my words closely, often repeating them. She also is aware of others nearby, and shows empathy when John loses his footing.

Naomi and I connect from the start. Whenever she sees me coming she enthusiastically welcomes me. Naturally affectionate, Naomi encourages me amid my meeting many new people. I reciprocate her care and we begin to mirror one another, holding hands as we interact.

Thomas - articulating self

During our first encounter, Thomas exemplifies his continuing ability to perform his preserved story to testify to his identity.

Thomas sits in his specially arranged art place, whistling and engrossed in colouring his picture. I introduce myself and he responds by welcoming me, launching quickly into reflecting on his life:

> *Thomas: I came on being something when I was only a little lad… Julie: So you've had an amazing life! Thomas:… and this little boy swam and I've been all over the world...because… Julie: Do you mind if I record your story… Thomas (strongly): No, no problem. Julie:… for your work? Thomas: yes, it's work but it's me...sounds a bit big headed but it's me. I'm a fabulous swimmer… No one has ever caught me up because I go too quick…Yes, I do and I am tall and strong and never been beaten… Julie: Wow! Thomas: I was minding my own business and the water was there to God knows where, and I was there on my lovely horse…behaving himself and there were 25 Arabs. They were aiming at me…and they thought themselves mighty men (lifts head and nods up and down and makes a face suggesting accomplishment/ pride)…But when I got going, they ran because with my arrow I don't miss… Julie: Were you doing your duty? Thomas: Actually, I was a policeman at that time. And they damned well did as they were told, or they ended up in prison...I've swum*

> *around the world. And I don't miss… Julie: I'm going to move on now. Thomas: It was a pleasure talking to you and if you're in that area and you call on me, I guarantee to give you some food and drink…*
>
> *Extract 6.14 (AT, RI, Home 1, AP, Thomas, 4/12/2017).*

Thomas is articulate, imaginative, demonstrative and proud of his many achievements, as expressed in his litany of life stories. He depicts his strength and ability to protect others, and to defend his territory. Intermittently I ask questions, extending his commentary, but say little, simply listening and making appreciative sounds to Thomas' intact verbal dexterity. His story sets the scene for Thomas' continuing sense of his identity, and how he lives with self-determination and self-worth in the present. Eventually I take my leave of Thomas, thanking him for our time together. With effusive courtesy, Thomas affirms being my host and invites me to come again. He has recognised me as an avid listener in reinforcing his identity, passions and essence.

John - expressing contentment and calm

In my observations of their demeanour, daily life for many people consists of what appear relaxed occasions, along with those that are more difficult. John encounters these varied experiences and reacts accordingly with his voice.

John sits at the dining room table after morning tea with his wife Frances, and two men. John's arms are folded, his eyes closed, and he is humming. As I join them John nods at my introduction, as his wife continues to talk:

> *Frances: I come twice a week, assisting with morning tea and lunch for everyone in the house. I know how much the carers and nurses do and so I help them out. I enjoy seeing everyone and chatting with them. John: humming. Julie: I have sometimes heard John humming. Frances: John likes to hum. John's family had a piano. They used to sing around it and were musical. (In response John looks at me.) Julie: That was special. John: nods slightly then with chin down seems to nap. Frances: For years we worked hard on an outback station. Now I continue to support John, understanding him, calming him down. John doesn't use many words anymore but I often know what he wants when he gets a bit aggro and wants to get his point across…One day we went to a footy function in the hall here. John got very distressed. He visibly calmed right down the moment we walked back into this dining room. It's good that he feels so at-home here. The staff are very good. Sometimes he raises his voice but then he calms right down with them.*
>
> *Extract 6.15 (AT, RFI, Home 2, DRm, John and Wife, 2/07/2018).*

Frances tells me significant details about John's life in this home. John appears tuned into our conversation, seeming to respond occasionally in briefly looking at me. His humming grows louder and then softer again, perhaps intimating his following and responding to Frances' words and our interchange. Frances explains John's humming from his earlier storied-life. In this situation John's humming indicates contentment and calm. I reflect later that John seems content with Frances mostly talking. But his difficulty getting his point across at times may be exacerbated by others speaking for him, provoking his intermittent "aggro" (POD, Book 1). However, Frances affirms that John now only feels "at-home here". She considers that her presence and that of staff, who also have a relationship with John, help restore his well-being through interacting with him. After this initial encounter with John I regularly sit with him and the other men having morning tea, seeking to build our rapport.

Mary – remaining in companionship

People have different routines in their day which staff accommodate and support each person to maintain. Mary rises mid-morning. When Carer Deidre hears Mary calling, she goes to assist her to get ready for her day. As they walk Deidre holds Mary's hand and seats her at the table with Sarah. As I join them Sarah is chatting and Mary sits quietly.

> *Julie: Hello, Sarah and Mary, I'm Julie…Can I sit with you both please? (Mary nods.) You two look very lovely today. Sarah: I like it. I do like her (nodding at Mary). She's handy (laughs). Julie: You are looking very nice, Mary. Mary: I don't feel good, feeling down. Lot of bad news this week. Julie: Oh I'm sorry to hear that… Mary: The trouble is that's it…people say, she's alright. They don't know what's inside… Missing daughters overseas. One day when they're ready they'll come back… Deidre brings meals for Mary and Sarah, and quietly sits alongside Mary listening and expressing concern. Gradually Mary eats her breakfast as we all sit together supportively.*
>
> *Extract 6.16 (AT, RI, Home 2, DRm, Mary, 18/06/2018).*

I have observed Sarah and Mary often sitting together, apparently sharing a kinship. On this first occasion of sitting with them I seek to communicate being relaxed and present. I notice they are well-dressed and affirm them both. Sarah affirms her friendship with Mary. Mary responds honestly about her emotions, with the insightful comment that people cannot see what is going on inside her. Even though Mary's feelings are negative, it seems as though she values Sarah and my companionship in being able to express them. She remains sitting with us and Deidre joins us. Deidre later explains that Mary has family difficulties which cause her significant emotional pain. When Carer Deidre and others notice Sarah or Mary expressing concerns or distress, I observe them come alongside each person with empathic and comforting presence.

This section has demonstrated that people may respond in various affirmative ways, revealing the significance of the encounter to them. Luke moved from being agitated and needing Anthea's company, to becoming relaxed during a drink and walk together, and voicing his characteristic humour. Naomi was warmly welcoming in her greeting and continues to express her enjoyment in her animated repetitive speech. Thomas was content in having an attentive listener and elaborated his story with enthusiasm. John responded to sitting with his wife, mates and myself at the table with his relaxed body position and facial gestures, and his contented humming. Mary seemed to value the company of those who would sit and listen as she shared her storied-life and sadness.

Thus far I have described the voice characteristics the person may use in initiating and responding in interactions and forming relationships. My observations and interactions with each person developed my understanding of their particular voice repertoire. In the following section I continue to describe the range of ways each person voices themselves, summarising each person's intact unique voice repertoire which I gleaned through our initial encounters.

6.4 Recognising Voice Repertoire

Due to spending time with people over an extended period of time and during a range of encounters across their day, I have collated an extensive series of observations and interactions with each person. As demonstrated already in Chapter 6, and will be shown extensively in Chapters 7 and 8 in the extracts of central participants, I have formed the following perception:

The person may use a variety of nonverbal language such as eye gaze and eye movement, facial expressions, embodied movement and gestures, smiles and sighs (Ellis & Astell 2017, p. 1). In addition I have found that the person may also use, either occasionally or regularly, verbal language in words singly, phrases, sentences and extended comments, often with a specific tone such as enthusiasm, humour, sadness or frustration; and/or regularly may use a blend of both non-verbal and verbal language. They may also uniquely enact their self, according to their ongoing personal characteristics related to their identity (Godwin & Poland 2015; Perkins et al. 2015), agency (Boyle 2014; Cahill & Diaz-Ponce 2011), and storied-life in interactions and relationships (Kontos, P et al. 2017). These ongoing personal characteristics of identity, agency and storied-life as part of the person's voice repertoire will be elaborated further in Chapter 7.

The person demonstrates an ability to express and/or enact these various aspects of their voice together in the one encounter, and often simultaneously. I have termed this function of the person's voice their "voice repertoire". My initial awareness and understanding of each person's voice repertoire informed the ways in which I engaged with the person in subsequent encounters, as we continued to develop relationship with one another. Only in the context of these relationships was I able to explore further what contributed to people's voices.

6.5 Insights of Staff in Promoting the Person's Voice

The insights and comments of staff illustrate the importance they place on knowing the person and supporting their voice, how they encourage and respond to the person's voice. Staff comments inform my understandings.

Capability Assistant Joylene defines her understanding of each person's voice:

> *Joylene: It's really important to remember in any care everybody has a voice, and has the right to be heard. I've learnt a lot listening and observing different residents. Voice depends on the person…vocal…or the way somebody moves or acts…facial expressions everyone has a way of expressing themselves…can become agitated... Staff might be the only ones to [interact] with that person for the day. So finding things they like to talk about. Also making sure you listen to people and hear what they're saying, however they can say it and respond to them… The more people talk the better they get at it as well. The better your listening and observations skills, knowing who you look after and looking for the changes…and how we can make a positive difference in their day.*
>
> *Extract 6.17 (AT, SI No. 2, Home 2, Capability Assistant, 16/07/2018).*

Joylene explains that the recognition of each person's voice by staff is their need and right in care. Defining voice broadly as how the person expresses themselves, she describes it in diverse ways. Ongoing learning through attentive and careful observation and listening enhances understanding of each person's way of communicating. In recognising that each person experiences changes, staff need to adapt their knowledge of the person to appropriately assess and provide for their needs. Many staff view their interactions as vital to the person. Regularly interacting with staff strengthens the person's ability through practice, ensuring a positive effect in their daily life.

As she sprays air-freshener and tidies the room, Carer Briony comments about what her practical efforts mean to her in supporting the residents. I then ask her to assist Miriam:

> *Briony: I like it to look really...Clean like their own home. I really take care (chuckling) of them a lot…I love them all (delight in her voice)…(comes to Miriam) Oh, do you want to find some cleaner clothes for baby? Miriam: Yes. (shows her) Briony (moving off): I'll get the wash basket…Let's send them to the laundry, [Miriam]… Miriam: Yes. Briony: What shall we put on baby? (holds a garment up) what do you think, [Miriam]? Briony: Bit bright? Miriam (uncertain): little bit. Briony (looks again): There we go, [Miriam], a matching set. Miriam: Yes (looks pleased).*
>
> *Extract 6.18 (AT, RI, Home 2, DRm, Miriam, 3/07/2018).*

Briony relates maintaining the lounge room's appearance to showing her care for each person. Made aware, she immediately responds practically to Miriam's need, bringing the pre-prepared washing basket. Miriam continues to choose clean matching clothes for baby, again enacting her agency. She relaxes and smiles appreciatively at Briony who has responded to her concern. I recognise Miriam's need to be acknowledged by staff and her positive reaction in response.

In the next extract Chaplain Sharon describes how the self-awareness of staff also facilitates interactions and relationships with each person:

> *Sharon:…[With] fairly simple words…if we [say a lot] people look confused…My body language for them is huge too. Because you don't want to be a threat or anything…Once you spend time you know the people that are very touchy that love a hug, and others might not. It's respectful of what's right for them…*
>
> *Extract 6.19 (AT, SI No. 3, Home 2, Chaplain, 8/08/2018).*

Sharon emphasises that staff's attention to their own verbal and body language impacts the person. People are aware and affected by a staff member's mood, sensing their aggravation, being too busy or not fully present. Such staff behaviour can lead the person to the same stressed emotions, low mood, or becoming withdrawn and silent (Cameron et al. 2020). Staff being self-aware also enables them to be attuned to the person and respond with sensitivity, respecting how they wish to relate with others at that time, and becoming aware of what they may be experiencing within and with others.

Many staff express how their values guide their valuing of each person, as Nurse Aggie states:

> *Aggie: I think it is important. They're still people…(ironic laughter). You know no matter what age or state. They've lived lives, done things that I would never do...It's just the way they are at the moment…and you know it doesn't matter…they're still alive, still with us…Unfortunately, I don't think society really values our elderly, [nor] the Government does…support them…so that there's a dignified level…so people aren't feeling like they're imposing…They still want everything that we want…*
>
> *Extract 6.20 (AT, SI, Home 1, Nurse, 18/12/2017).*

This extract represents the positioning of the person by many staff in each home, in recognising each person's ongoing presence, value and citizenship. Nurse Aggie advocates relating with respect to each person in the fourth age, due to the length and experiences of their life. Through their affirmative work staff demonstrate the importance of caring for people in this final phase of life. Several staff state their opposition to the devaluing and prejudicial attitudes towards older people which they consider is exhibited by society and government. Their choice to work in residential aged care is deliberate for many. To the best of their ability, they support and care for older people so they may continue to live a dignified and fulfilling life.

The hairdresser Deb (D) imagines how it is for the person having their voice:

> *Deb: Well. That is the whole reason that people are alive really, isn't it?…I think the reason that I'm trying to help here is just to get that message across…Anything positive that you do is because that person is significant. (Deb is crying and emotional.) That's – well (we sit in silence together).*
>
> *Extract 6.21 (AT, SI No. 2, Home 2, Hairdresser, 23/02/2018).*

In grasping the significance for the person in enacting their voice, Deb and I are deeply affected. Like Deb, several staff members speak of the transformation they witness in the person as they sit, attentively listening and observing them enacting their voice. These insights of staff recognise the right of each person to be acknowledged, respected and valued as a unique person with their voice as they participate in this residential community. In being attentive and responsive to each person's voice staff assist people to be well-cared for, comfortable and content, supported in their needs holistically, and to experience and enjoy the day as they wish.

6.6 Summary

In this chapter I have shown that forming relationships with each participant was an important stage of the research, and provided the foundation for the findings in this and the chapters that follow (Chapters 7 and 8). In our initial encounters due recognition of whether and how the person wished to relate was very important in respecting their choices, and thus preserving their dignity. Becoming aware of the person's voice repertoire, I began to mirror respectfully some aspects of the person's voice capability with them. This seemed to facilitate their responsiveness with their voice repertoire. Most people seemed to become receptive to me and accept me as an interested person seeking to interact with them. In reaching out to engage and form relationships the person appeared to express their desire to connect with others. Findings of this chapter have highlighted that the person often showed their appreciation and pleasure in engaging in interaction and relationship with me, other residents, family and/or staff members.

I have also shown in this chapter that there were many specific details in the ways each person engaged in initial interaction as we formed relationship. Some people demonstrated their intact ability in initiating to get the attention of others. Many enacted rituals of courtesy, greeting and interaction with me, friends, family and staff. Even in this early stage of fieldwork, people often enacted some aspect of their life that was significant to them, by expressing who they were through their gestures, ability to socialise in turn-taking, or a proverbial saying. Each person's voice repertoire appeared unique, demonstrating their individuality in their personal characteristics and use of verbal and/or non-verbal language. My findings in this chapter show that many people acknowledged another person they knew with a non-verbal gesture such as a smile, a wink, a wave, or their hands reaching out towards the other. Moreover, many people were able to accompany their embodied language with a verbal indicator, a word, words, or a phrase, reinforcing their opinion, choice, or needs.

This chapter has demonstrated that family or staff members were often attentive and responsive through listening, observing and intuiting to validate the person's voice. They often reinforced to the person a desire to understand and interact with them. Staff recognised the person's expression of voice as their right - the staff's responsiveness respecting their personhood. While many staff described and demonstrated the ways they promoted the person's voice, few were skilled in specifying the person's voice repertoire. Nevertheless, as I moved amongst people, I noticed each person and most staff greeting one another and interacting with cheerful friendliness, seemingly imbued with mutual respect and regard in sharing relationships. Chapter 7 shows that through the continuing development of relationships with each person over time, they revealed more aspects of their voice and their lived experience, in our encounters and in their interactions with others.

CHAPTER 7 VOICE IN DEVELOPING RELATIONSHIP

Introduction

This chapter builds on Chapter 6, continuing to explore how people with advanced dementia enacted their voices as we developed our relationships. In Chapter 6 I argued that people often took initiative, using social conventions and their voice repertoire to engage with others. This chapter extends the findings of Chapter 6 to show how participation with others in one-to-one and group interactions promoted the person's voice. Furthermore, this chapter demonstrates how the person often voiced their personal characteristics of agency, identity and storied-life. The commentary of family and staff members surround the voice of the person, portraying how they understood and promoted the person's voice.

This chapter in four sections presents the themes regarding how the person expressed or enacted their voice in relationships, during one-to-one and group interactions. These themes are: 7.1 'Providing Spaces - promoting Voices and Relationships'; 7.2 'Voice enacting Agency and Identity'; 7.3 'Agency and Identity facilitated by Staff - to be or not behaviours'; 7.4 'Voice through sharing Storied-life'.

7.1 Providing Spaces - Promoting Voices and Relationships

Over time, observational and interactional data showed the rhythm of daily life for each person and the dynamic flow of interactions between people. Interactional occasions were threaded through the data as people expressed or enacted their voices, one-to-one and in groups in various places within the aged care homes. I observed that these activities and places were the spaces that promoted people's voices and relationships. Gradually each person also recognised me from one visit to the next as shown in their facial expression, or a bodily gesture. Several people appeared to appreciate our developing relationship by sitting with, or accompanying me as I moved around. Other people launched into conversation as if resuming where we had left off from a previous interaction. I noticed that most people moved out of their room to the shared places independently or with the assistance of staff, unless their indicated preference was to remain in their own room. I observed that people congregated in communal places in chairs arranged by staff for this purpose or in their comfort chair.

Voices in reciprocal relationships

This sub-theme recognises that people expressed or enacted their voices with one another in reciprocal relationships. I noted that this happened as they got to know each other over time and spent lengthy times being together through the day.

Paul and John - voicing support to one another

I observe Paul and John often sitting together in the foyer or dining-lounge room. In the next extract they show how with their voice repertoire, they enact their mutual support and relationship.

Late morning I meet Paul sitting in the entranceway. He expresses to me his concern and critique of an agency carer who he had noticed not stopping to listen to him and others. John joins us and Paul includes him in the conversation:

> *Julie (John stands before Paul, his feet planted, his body moves backwards and forwards looking directly at Paul): Hello, John. How are you going? Paul (cheerfully looking at John): I know this is John… Julie: John you're looking well today... John: Mmmmmmmmm Julie: He's humming away… Paul (definitely and cheerfully): He's a good man… Julie: John could really help you. Paul: Well, I was thinking that… Julie: John you're really involved, aren't you? Paul: Oh, I wouldn't take it unless he was…I know John very well… Julie: John has a smile on his face... Paul (with great exuberance): Hello you, cheeky trousers! (John rubs Paul's hand) Julie: Oh, John, that is so beautiful. You needed that, Paul? Paul: Oh yes, I did. Julie:…such good friends. Frances: Come with me, father, and sit down for lunch… Paul: (looking at John) and I'm going to find the same place as you. Julie: See you both later. Thanks, John, for the smile!*
>
> *Extract 7.1 (AT, GI, Home 2, Passageway, John and Paul, 13/07/2018).*

This extract shows the close affinity between these two men. I observe that John seems to intuit Paul's unease, as Paul expresses his criticism. John focuses his eyes on Paul, moves towards him and stands in front of him, seeming to indicate his attention and care. Paul responds, affirming their relationship with an endearment for John. John's humming along as he smiles and pats Paul's hand suggests his reciprocal affirming response. I observe their embodied gestures evidencing a connection of mutual trust and understanding - John non-verbally and Paul with words. Carer Roy later validates my interpretation as he tells me about his observations of John with Paul and also other people:

> *Roy: John, he's a great man. He's actually improved. He used to get aggro, compared with what he is. He's very caring. He likes to help people and all that. He's actually a good calming influence. He just goes up when Paul gets irate and he relaxes him and settles him down.*
>
> *Extract 7.2 (AT, SI, Home 2, DRm, Carer, 7/08/2018).*

This extract demonstrates how Roy perceives John's strengths in enacting his relationships with and care for others, and particularly his support and help to Paul. Roy recalls that John reacted with aggression to others when he first came into the home. Roy compares how John has now developed relationships and become supportive of others who appear unsettled, including Paul. Previously, John's wife Frances has told me this home is where John now seems calm and content. She has noticed he has returned to enacting his care for others as he did throughout his life. Frances considers this is John's positive response to now feeling "at-home" (AT, FI, Home 2, Café, John's Wife, 13/07/2018). However, people do not always form relationships with one another, with some finding it difficult to relate with one another. This is Luke's experience with certain people, as the next extract demonstrates.

Luke - being unable to relate with one another

Sometimes Luke voices his reaction both verbally and non-verbally to me about another man not interacting with him (RJ, Book 1, 29/01/2018). I sit with him as another man leaves. Luke asks:

> *Luke (flat tone): What's he doing? He's awful, isn't he? Julie:…I guess we're all different. Luke: Yes, of course. All pieces…But he doesn't do anything for me… Julie: He doesn't talk with you? Luke: He doesn't try. He could do it if he tried, I think. Julie: Because you like a bit of a chat, don't you? Luke: Yes (considered). Yeh, I do (chuckles).*
>
> *Extract 7.3 (AT, RI, Home 1, DRm, Luke, 29/01/2018).*

In his vocal tone and words Luke is able to articulate his reaction of frustration and sadness regarding the other man not relating with him. He expresses his insight that there is no connection between them, voicing his uncertainty in what seems an unfamiliar experience for him. According to some staff and his son, Luke worked in community services and endeavoured to relate with and help everyone (AT, Ch, FI, Luke's son, 9/03/2018). I have observed Luke still engages in this pattern and appreciates developing relationships with others. As I affirm Luke's ongoing qualities with others he chuckles. My recognition of his personality seems to help him become cheerful. Our conversation seems temporarily to mitigate Luke's reactions. Staff tell me they provide listening and calming support also. I note that Luke regularly sits with others outside the café. On the same day as our previous conversation Luke is sitting with others. Seeing me from a distance he smiles, calling out to me, "We enjoy sitting together. We all know each other." (AT, RI, Home 1, Café, Luke, 29/01/2018). Luke states the significance he places on this gathering, in regularly choosing to participate, sometimes chatting, or enjoying relaxed silence with others.

Interactions were initiated between people in various ways through their day and seemed to build their relationships with one another. John and Paul valued their friendship and the support they gave to each other, expressed verbally and non-verbally. Luke articulated his struggle when he was unable to interact and form a relationship with another man who he encountered often. Conversely, Luke also enjoyed being with those with whom he had relationships. These extracts reveal the importance that many people continue to place on engaging in interactions and relationships with other people for their sense of meaning, purpose, contentment and well-being.

Staff promoting voices through relationships

This sub-theme shows the significant role staff played in promoting interaction and relationships with each person and in groups. As these following extracts show, the person was able to acknowledge, engage in and respond appreciatively to caring supportive interaction and relationships with staff.

Naomi - appreciating respectful assistance

Carer Lisa provides respectful relationship in coming alongside Naomi to offer morning tea:

> *Lisa: [Morning tea] for you, Sweetheart…I'll sit you up...Do you want me to help you with this one? Naomi: Yes. Yes, I would. I love them. Mmmm…*
>
> *Extract 7.4 (AT, RI, Home 2, DRm, Naomi, 29/06/2018).*

Lisa offers to assist Naomi with morning tea, rather than assuming she can take over, and Naomi responds appreciatively. Naomi and Lisa have a relationship spanning several years. I have heard Naomi greet Lisa saying, "You are gorgeous", indicating her appreciation of Lisa. I observe Lisa's care alongside Naomi, matching her tone of speech and body language, with eye contact and hands touching. Naomi is able to respond with clear words indicating her choices (POD, Book 2, 16/07/2018). This time of interaction, mostly non-verbal, demonstrates their rapport and harmony.

Luke - acknowledging one another

One afternoon Residential Services Manager (RSM) Ruth is welcoming and interacting with people gathering for a meeting. I observe Luke come up and smile at her. In response Ruth puts her hand on his shoulder, apparently affirming their connection (POD, Book 1, 4/12/2017). Previously I have seen Ruth spending time relating with residents. As a result she seems to be well-known and appreciated by many. On seeing Ruth, Luke and others move towards her. Rather than overlook residents Ruth greets them. In the next extract however, Ruth identifies that relating with residents is not always straightforward:

> *Ruth: I like to get to know the residents and spend time out amongst them. Oh yeah, I mean even myself sometimes I feel bad about that if I happen to be out showing some people around...There's [name]…,and [name]…like this morning…and [Luke]...You're trying to bring them all along with you while you're still having a conversation with others. So, it can get quite…,and yet they want to be involved in something…So they'll want to walk along with you.*
>
> *Extract 7.5 (AT, SI No. 3, Home 1, Office, RSM, 16/02/2018).*

As this RSM states, she exemplifies interaction and relationships with residents. I note she also encourages this approach by staff, verbally and in staff memos. These attitudes and actions seem to coalesce with the organisation's ethos to encourage each person to make the most of every day. However, as she and other staff indicate, engaging in relationships and interactions with residents is sometimes challenging and needs balancing with other daily role responsibilities and demands.

Some staff describe how they manage this balance, participating in interactions and relationships as a normal aspect of their care, including the personal care of residents. In this extract Carer Annabelle describes entering each person's room to begin their day:

> *Annabelle: I've been here twenty years. We're here for the residents…that's why… Going the extra mile, taking the time. Go in and explain and use eye contact. Ruth is wonderful, residents relate to her because she understands. It's about your relationship…respect, rapport, being flexible, going with the flow of each person and each day is different. Some staff react if the person says "Get out of my room", I find it's better to come back later. It's your approach then you don't have problems. You involve them, speak well to them, connect with them carefully. Not go in with a negative, frustrated attitude because they get defensive. But go in with "Good morning", open curtains a little and Luke says, "Thank you so much." Luke looks to you to make contact…*
>
> *Extract 7.6 (AT, SI, PhI, Home 1, Carer, 5/03/18).*

Annabelle articulates her reasons for her long-term work in the aged care home as based on her valuing of the residents. RSM Ruth has inspired her as a carer and Annabelle too prioritises being in relationships and interactions with people. She sums up this relational approach in a range of qualities that she seeks to enact in her work. Such qualities elicit calm and pleasant interactions, rather than the person's negative reaction to staff who are negative towards them. Annabelle describes her courtesy and respect facilitating the person's appreciation in response to her. Observational data showed that such positive interactions may happen as an intrinsic part of various activities during the person's day.

Timothy - relating during lunch

As they spend time together most days Carer Mercy and Timothy have developed a rapport, as shown in this next extract. Mercy assists Timothy with his lunchtime meal and explains:

> *Mercy (looking at each other): We have beef stroganoff, Tim. Would you like some? I'll get it for you (coming with his meal and assisting him). All good? Would you like some gravy?...You're a good singer, Julie. Julie: Thank you. And Tim's a good singer. You're a good singer too, Tim. (looking at him, and he smiles) You're*

> *smiling! Especially with the Beatles. (Tim chews as Mercy gets him a drink.) Julie: Was that tasty, Tim? Tim: (He looks into my eyes): Not bad. Mercy: A bit more and then a drink…Is it a bit cold? (as Tim grimaces). (Tim looks at me again) You have amazing brown eyes, Tim. Tim: (a deep throaty response. He focuses back on Mercy with the spoon and eating his meal, as we continue to sit quietly).*
>
> *Extract 7.7 (AT, GI, Home 2, DRm, Timothy, 9/07/2018).*

This extract demonstrates Mercy enlisting Timothy's agency and participation by explaining to him and asking him questions about the meal. This makes mealtimes a social experience between them. While letting Timothy concentrate on eating, I observe Mercy and him closely connecting with eye contact, facial gestures, and occasionally a few words. I begin to use Mercy's diminutive name for Tim, and he responds. I seek Tim's opinion by asking him about his meal. He looks directly at me saying, "Not bad", displaying his ongoing awareness of me, and his agency in his critique and verbal ability. As our relationship has developed Tim seems to have become more relaxed and responsive towards me with his bodily gestures, and occasionally expressing words.

During the family interview Tim's partner Charis critiques the actions of some staff, having observed them during lunchtime service:

> *Charis: Yeah, I've seen that sometimes you haven't seen those carers for a while. They go. Those who said, "I always have trouble in getting him to eat." I never have trouble getting him to eat, you know? I just think sometimes they're just sometimes too rushed and don't communicate with him.*
>
> *Extract 7.8 (AT, FI, Home 2, Tim's Partner, 27/07/2018).*

Charis has noticed some carers appear hurried and do not engage with Tim and others as they assist them with their meal. She has perceived Tim not responding to these staff and that they do not remain in the house. Charis recognises that assisting Tim calmly, communicating with him, and most of all knowing him, means that Tim responds by eating his meal.

RSM Sue later explains the necessity of selecting appropriate staff for the memory support houses:

> *What is of a concern to me is that we have staff that have the right skill match and sensitivity to their ability to understand and communicate and provide openings for residents to communicate in a variety of different ways. That's not easy. A lot comes from staff getting to know the residents which happens naturally for some people. We try really hard to select people that have that ability. We don't always get it right. Sometimes you've got to try things and then see how that goes.*

> *Extract 7.9 (AT, SI, Home 2, RSM, 8/08/2018).*

RSM Sue tells me management select staff who display interpersonal skills with people with advanced dementia, and the ability to get to know each person and facilitate them in expressing their voice. The RSM's comments resonate with the observations of Tim's partner. This praxis of the carer's engagement and interaction with the person encourages them to eat their meal. This activity enacts the organisation's ethos of supporting the person to make the most of their day.

Many people appeared to have developed close relationships with several carers, cleaners, chaplains and lifestyle assistants, responding affirmatively with words, a smile or attentive gaze whenever they appeared. As discussed previously, such courtesies and acknowledgement by staff seemed to promote the person's voice and positive demeanour. Naomi expressed her delight in her gestures and words to particular carers with whom she had relationship. Luke appeared animated when he met RSM Ruth and they exchanged appreciative gestures. According to Tim's partner Charis, he chose to eat when he was assisted by a carer who he knew and interacted with him. Each situation depicted staff members promoting the person's voice and the importance the person gave to interacting in relationship with them.

Places and group activities promoting voices and relationships

This sub-theme demonstrates the importance the organisation placed on providing various places and activities for diverse interactional groups.

Hair salon

One interactional hub is the hair salon, visited regularly by most residents. Hairdresser Deb has a relational and transformational understanding of her role, as she explains:

> *Deb: [The hair salon] is a meeting place for some people. Just get to know them, introduce them to each other. Listening, talking and just asking...They want to tell you the same things over and over again…You've got to act as though…it's the first time that they've ever told me and still stay interested…It's a bit sad as people change but what I do doesn't change…It only affects the way that I work, not the way that I speak or behave with each person…A lady came here yesterday...very anxious...At the end when she had her hair cut, washed and set she caught a glimpse of herself as she's walking past the mirror…looked for a good few minutes!*
>
> *Extract 7.10 (AT, SI No.2, Home 1, Hairdresser, 23/02/2018).*

The hair salon is a meeting place, with Deb defining part of her role as an interaction and relationship facilitator alongside each person. She seems skilled in introducing people to each other, listening, talking with and asking questions to engage them. Envisaging every encounter with fresh appreciation she communicates her interest and affirms each person. In consistently positioning the person as capable of relating with others, Deb validates their personhood and promotes their participation. Deb gives the example of one woman’s hairdressing experience, resulting in her enhanced self-esteem and demeanour.

Larger group activities

In both the homes participation and interaction are important in group activities planned and facilitated by staff. I noted my observations of people involved in larger activities facilitated by staff:

> *According to their preferences people are invited, assisted to attend and participate in various activities. Craft, music and singing, exercise and church activities are organised weekly. I observe that each activity has components of interaction, and there is at least one group activity each day. Each person takes part according to their capabilities and capacity. Group facilitators, such as lifestyle or capability staff, the chaplain and volunteer assistants, are attentive to people’s needs and provide one-to-one support. People seem accustomed to accepting others’ prompting to have a go or wait their turn in bowling and exercises. People call out their comments and chat with those alongside them. I observe them sharing purposeful and relaxed fun and social interaction. When someone becomes frustrated, a facilitator quietly comes alongside, reassuring, and calming them.*
>
> *Unless they prefer to be in their room or sit elsewhere, people are assisted to sit with others at the dining tables for refreshments and meals. I observe them interacting with one another intermittently. Some people sit or move around alone, responding to a staff member’s greeting, signifying the value of mutual acknowledgement. People often sit together in the lounge, dining rooms, or courtyards with familiar music playing in the background, providing a relaxed ambience.*
>
> *Extract 7.11 (POD, Book 1 and Book 2, GA and ARm).*

Both homes provided an intentionally interactive and relational environment which prompted the person to engage in interactions and relationships with others, if they chose to do so.

Smaller group activities

Some people needed smaller groups to enable their participation and cater for their needs for support and companionship at the end of the day. This was so for Philip and Luke as described in the next two extracts.

I find out sometime later from Lifestyle Coordinator Prue that Philip was a newcomer to the home only months before we met. In this extract Prue explains that Philip has been calling for his wife:

> *Prue: Just so you're aware, he will call her [name]…Quite often four o'clock in the afternoon he'll stand up here [name, name]…I'm about the only one that knows to go out there and say, "No, [name] is not here, she'll be here tomorrow morning". Everybody else goes "who's [name]?" When you're talking about how do residents [voice]… especially those with dementia. That's one of those little things that I try and pick up on. That they've got a specific name they use for someone…This information is in the Care Plan. Ninety per cent of people don't read them…Yes, you get some carers that come in and want to know the resident…if they've got that insight...*
>
> *Extract 7.12 (AT, SI No.2, Home 1, Lifestyle Coordinator, 8/01/2018).*

According to Prue, in the late afternoon Philip calls out for his wife. Prue expresses dissatisfaction that few staff appear to understand or respond to Philip, having not read his social-spiritual care plan. Prue is responsible for collating this information so staff get to know some details about the person and their needs in order to understand and care for them. I reflect later on Prue's comments that Philip apparently has found moving into this aged care home disruptive and disturbing. I observe some staff provide supportive relationship with Philip during the day, and he responds cheerfully towards them. But the late afternoon is his unsettled period, when he voices his need for more support.

Like Philip, Luke is also displaying his need for support in the late afternoon. Again the Lifestyle Coordinator Prue explains that Luke is finding some groups difficult, due to his hearing challenges and cognitive changes. In response to Philip, Luke and others' social and emotional needs, lifestyle staff organise a new small group in the late afternoon (AT, Luke, 5/01/2018). Seven of us, including Philip and Luke, Lifestyle Assistant Bonnie, and volunteer Jack, gather around a table working on a difficult jigsaw of polar bears on an icecap. Luke comments:

> *Luke: Terrible, isn't it? (Luke looks at the jigsaw puzzle pieces on the table with an exaggerated grimace.) Julie (humorously): Well you're trying really hard but it's not easy! …What do you think, Luke? Luke: You are very capable people… Philip (nodding as he looks at the pieces): Yeh well, you made right… Julie: Thoroughly good, isn't it? Luke: Very good… Philip: No trouble at all. Julie:…You two encourage each other… Luke (to everyone): You are very clever. Julie: Luke, you're just enjoying being here, aren't you? Luke: We came in here a long time today, didn't we? Bonnie: Yeh we did…It's lovely to see a smile on your face. Luke: Is it? Bonnie: Yes, it's very precious… Luke (as we stand to leave): How do we part? How do we found… Bonnie leads everyone out as Luke and everyone follow her.*
>
> *Extract 7.13 (AT, GI, Home 1, LRm, Luke, 2/03/2018).*

I observe that the people in the group find this activity engaging and companionable. Each person is engrossed, evidenced by their participation with words and facial gestures, laughter and turn-taking interactions for the entire hour. Philip and Luke make their characteristic affirming comments regarding others. Luke smiles and clearly affirms our prolonged and pleasurable engagement together. As we leave, I observe calm in each person as they go off to dinner contentedly together.

A second small group activity at Home 2 in the activity room is “The Men’s Shed”, facilitated by the capability assistant and volunteer Clive, who describes how men enjoy socialising in the group:

> *Clive: We usually seat Paul and Jock together. Yeah, I won't say it - nobody else understands what they're saying. But they do, they talk on the same wavelength together…Paul will say something and stop, and Jock will pick up and say a line and then laugh away. Then Jock will go (makes a facial expression)- a response to what Paul has said. I mean I must admit I'm lost (chuckles). Julie: Well it's really important …They're taking turns because that's what we do all the time and don’t notice…. Paul and Jock have a good laugh together? Clive: Oh, they do…Yeah, they're always chattering away…You say well what's the joke? …*
>
> *Extract 7.14 (AT, SI, Home 2, Café, Volunteers, 20/07/2018).*

Clive gives the example of Paul and Jock conversing together. Clive and others do not understand their words, but Clive discerns them sustaining an elaborate conversation with turn-taking, facial gestures, a joke and laughter, displaying an understanding between them. Another Volunteer, Pam describes the changes she has noticed in Jock. “Jock was just down the street from me and I rarely saw him out. He has completely changed since living here.” Pam speaks of the trans-formation she has seen in Jock as he now freely socialises and jokes with others (AT, GI, Volunteers, 20/07/2018). Clive describes Paul and Jock showing their retained interactive capabilities, capacity and relationship. Their easy interaction is a sign of being comfortable and content in community with each other and others.

Home 2 has also adopted “Montessori principles”, whereby the intact capabilities of each person with advanced dementia are supported “through activities encouraging their engagement, interaction, meaning and purpose” (Elliott 2011, pp. 100-1).

> *These activities include a gadgets board to operate and move; coloured buttons and wooden beads to sort; folding napkins and rolling bandages. Each day the capability assistant places displays of objects on the various tables. The procedure is for a carer to facilitate, engaging a person or group in an activity. I observe that a facilitator is present sometimes.*
>
> *Extract 7.15 (POD, Book 2, GA, ARm, 5/07/2018).*

One afternoon Capability Assistant Joylene arranges a circle of men in the lounge room. I join them. Carers move through, sometimes stopping to interact with people. Carer Mercy sits chatting with John. I watch Paul roll bandages, “reminiscent of rolling up the ship’s ropes”, says Capability Assistant Joylene. As Paul rolls, another man joins us and sits watching Paul as he teaches me:

> *Paul: It depends on your windows. (Paul chuckles)…So it’s in very nice. But it doesn’t give the time…Not a ship…(demonstrating rolling, Paul looks at me) Julie: That’s very good. Paul (with a nod and smile): That’s all you need! (pointing to the bandages) I knew where it was because I’ve been doing it far too… Julie: just by holding it… Paul: Ends and I can…I tell you what…My yes… Julie: Well you’re very good! Paul: And I did it! (his hand indicating the rolled bandages) Get away with you! (Chuckling again).*
>
> *Extract 7.16 (AT, GI, Home 2, LRm, Paul, 3/07/2018).*

Paul indicates his pleasure with comments and chuckles, as he continues rolling in his familiar embodied rhythm of hand movements. Paul shows his ability in becoming my teacher, perhaps reminiscent of mentoring many sailors. He mocks my incapability and uses a proverbial saying and we laugh. Paul displays several intact capabilities voicing his humour, reminiscence, retained rolling skill and the capacity to hold others’ attention. In the background rock music is playing, “Unchain My Heart” with Joe Cocker, seemingly an appropriate metaphor for the occasion. This planned, yet simple relaxed activity provides a light-hearted and meaningful time for people to interact with one another and affirm their relationships.

On another morning Tim and some other men are assisted by Capability Assistant Joylene to the table where, as usual, she has placed a gadget box, with all sorts of moving pieces nailed to its sides that can be manipulated. She asks me if I would like to join them at the table. Mostly the men sit looking at the gadget box. I reach out and touch a gadget, showing Tim and the others how it works and encouraging them to do so:

> *Julie: What do you think, Tim? Lots of different pieces on this one…(Jock starts speaking to Tim.) Julie: Jock likes speaking with you, Tim…(Tim touches something on the gadget box.) That’s very interesting, isn’t it, Tim? (Tim looks at Jock and I watching and keeps moving the gadget in response. Julie: That works well…Did you have a toolbox, Tim? I think you did. You can press this and see if it works.*
>
> *Extract 7.17 (AT, Home 2, LRm, GA- Gadget Box, 5/07/2018).*

I seek to engage Tim with a question. He looks at me as I push buttons on the calculator.
Tim then moves the objects and Jock also responds by moving a gadget.

I later write down my observations of this activity compared with other activities:

> *Activities such as singing, church and exercises are always facilitated and there is participation and interaction, whereas table activities are usually not facilitated. I only occasionally see people touching the displays on the tables in the activity room. A carer may participate only briefly. In response some people do not engage at all with the objects and interact with each other only briefly. After the carer's brief involvement they again sit passively together for lengthy periods, perhaps resulting in less benefits for them. When someone such as a staff or family member interacts with the person or group regarding the objects, they seem to become more interested and engaged with the objects, and interact with one another. Today as I sat with Tim and the other men I facilitated their engagement with the gadgets. Tim responded to my and another man's affirmation. He looked at me, then reached out to the gadgets and engaged, moving them for several minutes. When another man came and spoke with him Tim maintained eye gaze with him. I noticed the men also came to the end of the activity session showing contentment, with smiles, gestures, eye gaze with one another and some of them using positive words. It seems to me that facilitation by a staff member is needed in each session of table activities. Through interacting, encouraging and affirming each person's participation staff enhance the involvement, interaction and friendly atmosphere between people.*
>
> *Extract 7.18 (POD, Book 2, 5/07/2018).*

In sum, the provision of pleasant places to sit meant people had ready-made venues to gather, interact and develop relationships with one another. Moreover, when staff conceived of these areas as places for interaction and their role as facilitators, they also became engaged. The hairdresser conceived of the hair salon as a relational place and herself as a facilitator of people meeting and chatting. Thus the person looking good and feeling good about themself becomes linked with relating with others. In the larger group activities, having several group facilitators enabled everyone to participate calmly and encouraged each person's capabilities in interacting. The presence of a group facilitator made a positive difference in the smaller activities, encouraging a relaxed and safe space for everyone to be included, to participate and interact with one another. Here people expressed and enacted their voices and developed relationships with one another and staff. However, it was apparent that not all carers considered their role to be facilitating activities.

Voicing need for company and relationship

This sub-theme responds to some people indicating their need for and appreciation of someone's company, rather than being alone, as illustrated in the following example.

Naomi - needing companionship

One morning I arrive in the dining room. Nurse Jade speaks about Naomi "not having a good morning, not herself", suggesting I might find out what is wrong (AT, DRm, Naomi, 2/07/2018). I go to Naomi, sitting alone in the dining room, and immediately she exclaims:

> *Naomi (warmly): It is nice! Oh hello…..Lacalacalaca lake (sic)… Julie: Mmmm. Naomi: Mmmmmm. It would be nice to see on your outs… Julie: Thank you, your beautiful smile today. Naomi: Yeees! (warmly). Julie: And thank you for welcoming me. Naomi: Be nice!...Yes, it would be. Julie (emphatically): Well, it's nice to see you again, Naomi. Naomi: You have a very nice, nice… Julie: Are you feeling comfortable today? Naomi: Yes, we are mmmm....So we'll have da da da (rising inflection like making a list)…And we'll put this, this, this is alright. Julie: That's good. Is this your napkin? Naomi: Is it? (laughing together) Yes, you'll get it!… Julie: Yeh, what do you think? Naomi: I don't know. I can't see any wadi, wad, wadi (sic)…I don't know what goes on? Look at all the people that want to… (pondering in her voice). Julie: They've just woken up and they're getting up slowly…(feeling her hands I wrap Naomi in her blanket) You're a little cold? Naomi: Yes, it is…So, we'll have to go, go, go go. I suppose. This goes this and plea and play and may and may. There we are (as a carer walks past). Go, go, go, go (laughing)… Julie: oh you have such a lovely laugh and find great joy in everything. Naomi (strongly exclaiming): Of course I do!…Heavens…*
>
> *Extract 7.19 (AT, RI, Home 2, DRm, Naomi, 2/07/2018).*

Seeing me Naomi visibly brightens, using animated words and facial expressions. Naomi seems motivated to initiate a plan "da da da" for being together. We begin to converse and laugh as I respond to Naomi's comments and ask her questions to encourage her responses. Naomi is able to verbalise her concerns clearly in whole sentences in not "see[ing] any wadi" (sic anybody), and not knowing what goes on. Is she referring to carers being busy and not stopping in saying, "Go, go, go"? Her falling vocal inflection; "I suppose", suggests her disappointment. My interpretation seems confirmed when Naomi notices a carer passing, "Go, go, go…", perhaps as her critique. I affirm Naomi's laughter and joy and she aptly and strongly agrees. Naomi's spirit seems to have lifted during our time together, suggesting that she was feeling lonely and her need was predominantly to relate with someone. I relay my perceptions to Nurse Jade to consider.

Naomi's husband Beau is affirming of some staff as he notes Naomi's positive relationships with, and responses to them:

> *Beau: [Naomi] can speak but a lot of it is gobbly-gook (chuckling). I don't understand. She's good today. She's very interested in the staff here…I come here every*

> *day. But I can be sitting with her and all of sudden she sees some of the staff and she'll smile at them…Naomi (looking and nodding at staff nearby comments): Yes there, there, there.*
>
> *Extract 7.20 (AT, RFI. Home 2, DRm, Naomi and Husband, 6/07/2018).*

Beau expresses that he often finds it impossible to comprehend Naomi's words. Yet in this extract Naomi shows her capability in aptly following and interpreting the verbal language of Beau. Using her acute awareness and observation, Naomi even extends Beau's comments by nodding at staff who are in the vicinity as examples. In indicating her acknowledgement of each staff member Naomi seems to affirm their significance to her.

Chaplain Sharon regularly sits with Naomi and recognises her variable moods:

> *Sharon: You can definitely know within a second her feelings. If she's angry a certain look. Or worried, creases on her forehead, and looks lost in her face. Then the next time will be this warmth and oh, you're here. So, I'm being aware and mirroring that...We hold hands. If she is sad I will verbalise, "oh sad". Then hopefully that companionship, you're not alone. Might only last a little while and then she starts smiling. So, it's that being where they are at…*
>
> *Extract 7.21 (AT, SI No. 2, Home 2, Staff DRm, Chaplain, 8/08/2018).*

Sharon and Naomi appear to share a reciprocal relationship. Consequently Sharon has become attuned to Naomi's non-verbal indications and often recognises Naomi's current feelings. Sometimes Sharon notices a mingling of pleasure with sadness in Naomi's words and facial expressions. Guided by knowing each other, and her attentive observations, Sharon provides appropriate pastoral care. Sharon notes that in another's company Naomi becomes happier, resonating with my previous interactions with, and observations of, Naomi.

Hannah - needing special relationship

Some people express their need to hold and cuddle a doll, dog or teddy, and/or they may express their need for a specific person, as does Hannah. In subsequent encounters with Hannah, she again focuses on her teddy. In this extract Hannah tells me how much it means to her:

> *Hannah: And I take him with me. Julie: Yes beautiful. I know when you go to concerts you always take him with you as well… Hannah: I just wish my son would turn up, but I don't think so… Julie: Oh OK….He obviously means a lot to you. You love him very much. Hannah (quietly and definitely): I do…*
>
> *Extract 7.22 (AT, RI, Home 2, ORm, Hannah, 19/07/2018).*

Hannah responds in our conversation, again indicating the importance to her of her teddy's companionship. She immediately sounds pensive as she declares she misses her son and wants him to visit. Her sadness appears embodied in her coughing. Hannah seems to voice her need to fulfil this close relationship with her son. The tactile embodied companionship of her teddy seems to suggest the teddy may be a substitute for her son. In acknowledging her teddy and her son, I affirm their importance to Hannah.

Sarah - needing to share concerns

Some people expressed or enacted their need for space in which to share their concerns, as Sarah articulated in the next extract.

During afternoon tea Sarah, Mary and I sit together chatting. As I am about to leave Sarah notices and delays me:

> *Julie: Alright. I'll see you in a bit. Sarah: You know now I realise I'll need that help. Julie: Are you right with that? Sarah: I doubt it. I've got one of theirs. I can't find the doing the other. Julie (concerned): Ok Really? Is that worrying you or is that OK? Sarah: It will be worrying me a bit…It's just that I wanted to go home. Out of there. I liked it home…Well, I didn't have time. I haven't had time…They've been busy. They've gone hard. I don't like it. I don't want to do it. Oh well, no point (pointing to the vase of flowers). I put all of this out.*
>
> *Extract 7.23 (AT, RI, Home 2, DRm, Sarah, 2/07/2018).*

Sarah indicates she needs to talk and wants me to stay. Perhaps others being "busy" and going "hard" means there is no time to sit together and talk about her concerns with others, supposedly staff or even her family. Previously Sarah had commented about the challenges in the home in losing friends, seeking to be included, and feeling like an outsider (POD, Book 2, 18/06/2018). Her comments now express her love of her former home and wanting to return there, but not being able to. Pointing to her flower arrangement Sarah laments. Perhaps Sarah indicates her efforts are unnoticed when others are too busy; and/or maybe she feels her action has no purpose when she misses her home. I continue to sit with Sarah. My eyes sometimes gazing into hers and listening attentively, I empathise as she states her concerns.

Some carers tell me Sarah appreciates sitting and talking with them. Carer Janice makes time to listen to Sarah who sometimes talks about her hometown (POD, Book 2, 2/07/2018). Carers like Mercy realise that if a person appears sad, unsettled or demanding, they may be voicing their need for companionship and interaction with their family or a staff member as this extract describes:

> *Mercy: How easy it is to get frustrated with everything if you are just looking at the surface…you just pick up maybe ten per cent of what they are trying to say. Maybe you end up with the wrong response…or understanding. So this man was an accountant…All…knew and respected him…I told her, "He's asking for cup of tea, all the time coming to you. He wants that attention. He wants you to sit down with him with that cup of tea. Not just make a big jug full of tea and put it in front of him.*
>
> *Extract 7.24 (AT, SI, Home 2, Carer, 12/07/2018).*

Mercy states that staff may not engage with the person, to understand their underlying situation and their needs. Instead staff may focus on their mounting frustration at a person's repeated requests. In their daily praxis some staff take time to stop, sit down and have a drink with people. This deeper relational response transforms the encounter from being a brief task of giving a drink, to one of sharing company and interaction. Mercy guides other carers to be attuned to and engage with the person, to go deeper in understanding their needs for companionship and to provide relational responses. Otherwise she considers that staff may miss the person voicing their loneliness and need for social interaction and relationship. This experience can become reciprocal since staff may benefit in being with the person, like Naomi, enjoying their cheerfulness and lifting one another's spirits, or simply appreciating being together.

In summary there were various ways people expressed or enacted their need for company. Naomi's mood appeared low when she was alone, but lifted when carers or capability staff sat with her during refreshments or lunch. Hannah stated her specific need for her son, and apparently endeavoured to meet this through the presence of her cuddly companions, particularly her teddy, holding him close. Sarah needed to sit with staff who listened to her share her desire to return home. Some staff, like Deidre, Janice, Lisa, Mercy and Roy, seemed skilled at recognising the person's need and took time to sit with them and interact in relationship.

7.2 Voice enacting Agency and Identity

This theme shows how the person expressed or enacted their personal characteristics of agency and identity in their opinions, choices and way of being through their day (Killick & Allan 2010). In our interactions the person's agency in the present appeared to be closely associated with aspects of their identity, regarding their history, lifestyle, and storied-life. In articulating and enacting their agency, the person also voiced their desire to maintain their unique identity. This section describes findings from the data regarding the person voicing their agency and identity in three sub-themes: through awareness and critique, personality traits and rituals, and when relating with their family.

Agency and identity through awareness and critique

This sub-theme indicates that some people were able to express their agency in communicating their awareness and opinions of the care they received. The following extract demonstrates Philip's intact awareness of others and his environment, and his retained agency in making his critique.

Philip - making his critique

During our walk Philip comments with an uneasy tone:

> *Philip:...go back home…go back up that way, don't they? Julie:…are you wondering where home is? Philip: yeh…the pain turning circles…a few ks when the bad's going and switch on that and talk about when you stop you stop, and they're not all working. And you can't find them…and they go black flap (sic) and woo woo woo (sic). Julie: Do you wonder where they've gone? Philip: yeh of course I'd love to know where they were. Of course, want to know what the coast (sic).*
>
> *Extract 7.25 (AT, RI, Home 1, Passageway, Philip, 15/01/2018).*

Philip articulates his awareness on our walk. I respond empathically by looking at Philip and using Philip's word 'home'. He voices his unease in "the pain turning circles", perhaps physical and/or emotional. Philip seems focused on describing his difficulties, commenting critically, "They're not all working" and not finding them, suggesting he refers to staff. Perhaps he looks for a staff member to slow down or stop with him, but cannot find anyone. "Woo, woo" is a jockey's expression to slow the horse or stop it. My interpretation of Philip's words, grimaces and gestures suggest he is critiquing his negative situation. If so, his criticism and current experience contrast with his earlier storied-life in enacting his agency and identity in his close familial relationships and long-term community service towards others. I suggest that in his apparent criticism Philip seems to be voicing a counter-narrative of the need to slow down and stop, to be attentive to people and their needs when staff and their care seem to be absent, or maybe in a "flap". In seeking to understand and interpret his words I observe Philip's frustration in his grimaces and definite tone. I seek to listen carefully and empathise with him.

Agency and identity prompting my reflexivity and re-positioning

In this sub-theme I continue to signpost and demonstrate my reflexivity trail. I identify several occasions when the person in their words and actions prompted me to be mindful and reflexive of my behaviour, and to re-position myself in our relationship. I realised this after interactions with a resident and others, when I replayed the audiotape and heard myself. Reflexively I became aware that during our interaction I had assumed a position of leadership and power imbalance demonstrated by my rushing into speaking over or speaking for the person, or not including them, usually when I was speaking with staff. This happened when I was about to leave Lydia one morning.

Lydia - revealing her need and my disregard

Carer Annabelle, on her day off, arrives with her little granddaughter to visit people. I am distracted with greeting them, leaving my recorder briefly on Lydia's lap. Later I play the recording back and hear Lydia making a sound of disappointment and calling out as she responds to hearing the sounds of our greetings:

> *Lydia: (letting out sighs)…Is that a little baby? (When I return to Lydia after a short time I conclude my time with her.) Julie: Thanks so much, Lydia, for having me. I have to go now. Lydia: You're welcome!*
>
> *Extract 7.26 (AT, RI, Home 1, Dining Room, Lydia, 1/12/2017).*

Annabelle has "gone the second mile" on her day off, bringing her granddaughter for a social visit with people, and they welcome them both. Unfortunately, we do not include Lydia. Later I am disappointed by my oversight realising how I have overlooked Lydia in my interaction with the off-duty staff member. (RJ, Book 2, 1/12/2017). In becoming mindful reflexively I recognise my own easy fallibility in marginalising the person by ignoring their presence and participation (see Extract 7.31 with my analytical comment). Nevertheless, Lydia seems to be gracious appreciating our being together with her parting saying, "You're welcome".

During a much later conversation with Lydia my ignorance becomes more apparent to me. Lydia talks about her earlier times spent with her grandchildren:

> *Lydia: What about yours, alright? Julie: Our girl has four children. Lydia: (surprised) Four? Julie: We have four grandchildren. Lydia: Lovely. If you don't have work to do it's alright. Julie: Yes. I like spending time with them. It's very good…Do you have grand-children? Lydia: They used to stay with me. Julie: What did you do with them, did you read them stories? Lydia: Stories and sometimes we play with the little baby…You live here? Julie: No I don't live here, I just come here to sit with people and chat, and do my study. Lydia: Alright. Next time you are here come to talk. Julie: Oh thank you, Lydia. Lydia: To share. Julie: I will come. Lydia: Thank you very much. Pop in every time you're free.*
>
> *Extract 7.27 (AT, RI, Home 1, Dining Room, Lydia, 22/01/2018).*

In telling our family stories and Lydia's regard for mine we experience a spiritual connection with each other. Lydia voices how she had spent former days looking after her grandchildren. I realise how much her grandchildren mean to Lydia. In this I also recognise again how easy it is to be careless in not including Lydia in that earlier time with Annabelle and her granddaughter (RJ, Book 1, 22/01/2018). Moreover, I could have learnt these details about her family from her social-spiritual care plan much earlier to facilitate our interaction and developing relationship. Philip also prompts my self-reflexivity on another occasion.

Philip - prompting my self-awareness

Enacting his agency, Philip has initiated our walk (POD, Book 1, 19/01/2018). As we go along, we meet some staff who recognise and speak with me. After they move on Philip expresses criticism of the staff and me for not including him. This has hurt him, indicated in his words and tone, “It’s all on you, not on me. Still expect.” Unfortunately, I miss his strong critique until I replay the recording later. This is another instance of the recorder being the channel for the person’s words and actions, that on hearing them prompt my self-reflexivity as researcher. I had not realised our interaction had excluded Philip. I reflect how easily I become complicit in enacting stigmatising behaviours (AT, RI, Home 1, Passageway, Philip, 19/01/2018). In future I pay closer attention to including Philip and others, and positioning myself as a supporter rather than initiator (RJ, Book 2, 19/01/2018).

Being reflexively mindful facilitates me in enacting an ethics of care as a researcher towards participants in ensuring their recognition, being respectful and including them.

Agency and identity through personality traits and rituals

This second sub-theme recognises that the person’s agency was also evident through the expressions and/or enactment of their personality traits and personal rituals, as exemplified by Philip in the next extract.

Philip - continuing love and service

Philip enjoys chatting during our regular walks together. Usually he courteously asks to hold my bag:

> *Philip: Do you want me to carry it for a while? Julie: Oh, thank you. Philip: Yes, let me carry it. (He takes my bag and pretends it is weighty in his gesture and tone) It’s heavy! Julie: Heavy?…Is it too heavy for you? Philip: Yeh. Yeh. Julie: alright? Philip (with humour): Sure, sure. Good. Julie: There’s a bit of sunshine outside. Philip: So good it’s a bit of sunshine too…But the arms are a bit heavy. Julie: If it gets too heavy you tell me. I’ll take it from you. Philip (stands tall, cheerfully): It’s fine, fine. Beauuuuteeful! (emphasis) Julie: Well, thank you…*
>
> *Extract 7.28 (AT, RI, Home 1, Passageway, Philip, 15/12/2017).*

Philip demonstrates his agency and sense of humour in his extended performance of exaggerated courtesy with my bag. His identity is often displayed in his courteous rituals towards me and others. Participation in household tasks are also an expression of Philip’s personality traits and daily rituals. For example, Cleaner Valerie tells me she regularly goes outside with Philip to water the garden and sweep (POD, Book 1, Cleaner, 23/02/18). Valerie has learnt from Lifestyle Coordinator

Prue that Philip did these tasks with his wife at their home. Valerie has realised how important it is to Philip's agency and self-worth to help her in ordinary household routines. This helping activity reinforces Philip's enactment of his identity and personality traits, in supporting and serving others and contributing to this community.

When I sit with Philip and Phoebe she describes their life and the man Philip has been and continues to be:

> *Phoebe: He's a lovely husband and a lovely father. Worked as Justice of the Peace for forty years. When he finished, he received a letter of thanks from the Minister. Philip: Yeh, yeh. Phoebe: And then he's been the longest serving councillor…a tennis coach he used to take our kids. He has lost that…speech. That sense… Julie: You greet each person you meet, Philip. Philip: Yes… It's nice to say the nice…*
>
> *Extract 7.29 (AT, RFI, Home 1, Café-Courtyard, Philip and Wife, 3/03/2018).*

This extract reveals that Philip's life has been devoted to his wife, family and community. His identity is demonstrated in his love, leadership and dedicated service to others. Philip shows his ability to follow Phoebe's comments and my affirmation. He responds demonstrating his continuing agency and identity in making a simple profound statement about the importance of being nice.

Agency and identity encouraged by family

This sub-theme identifies that some family members recognised and encouraged their relative's continuing expressions or enactments of their agency and identity, as demonstrated by the following three exemplars.

Miriam - supporting capabilities

On one occasion when Miriam, her daughter Lynette and I sit together, Miriam chooses to face the main entrance. Lynette laughingly describes how Miriam watches people coming and going, commenting on their appearance:

> *Lynette: Oh yeah. You'll probably know what she thinks because she'll tell you. Some-times the filter doesn't work very well…Miriam: Let you know (chuckles)… Lynette: She has always been very chatty and that hasn't changed...we'll go out for lunch, "Have a look at that person." [I] put the hand up, no…She does a lot of looking and commentating. Julie: You're a great observer aren't you, Miriam? (She laughs)… Miriam: Let you know.*
>
> *Extract 7.30 (AT, RFI, Home 2, Café, Miriam and Daughter, 8/08/2018).*

Lynette identifies those features of her mother that have altered, and those that remain. In Lynette's regular visits and taking her to see family nearby, Miriam continues to maintain her social abilities with family through relationships. In this home Miriam is able to move about. She positions herself where she can observe and be "chatty" with whom she chooses, showing her continuing capability in her agency. Miriam demonstrates ongoing ability in following her daughter's and my comments regarding herself. She aptly extends them and repeats her agreement regarding her continuing agency and identity, with her humour.

Lydia - understanding current feelings

When Lydia, her son Theo and I meet together, he explains the gradual changes in his way of interacting with his mother to have meaningful engagement:

> *Theo: And one of the first things that happened was that she couldn't read…Mum could with phone numbers know that was a 2, but she couldn't link that to the next number. Lydia: It's not easy that…(Lydia puts her finger down and up)… Julie: It didn't finish when you noticed the difference in mum - she still continues. Lydia: I think I something like that (sounding strong as she holds her hands together). Julie: You feel like that? Lydia: Change. Now we stay here.*
>
> *Extract 7.31 (AT, RFI, Home 1, DRm, Lydia and Son, 22/01/2018).*

In this extract Lydia's son talks of earlier changes in his mother's capabilities and limitations, leading to her moving into this aged care home. Lydia is able to follow Theo's words about using a phone and demonstrates appropriately with her finger actions. Lydia also confirms their decision that this care setting is now where she lives.

Theo describes how comprehending his mother's meaning is challenging for him, requiring patience:

> *Theo: It's more challenging to have communication two ways...for the receiver as well. Often the message comes across in parts, not necessarily all related. So that's a challenge as well. So, there's a lot of patience needed…I tend to get a sense of the overall flavour, more than specifics maybe…It gives me a measure of how Mum's feeling for the day…The hardest thing is…she doesn't recognise my sons, or our nephews and nieces now…Not sure why that is because she was very close to them...That's hurt them really badly…and they no longer visit.*
>
> *Extract 7.32 (AT, RFI, Home 1, DRm, Lydia and Son, 22/01/2018).*

Theo gauges his mother's current state of being and her feelings at the time by piecing together all her comments during their conversation each time. He laments Lydia's lack of recognition of her grandchildren as young adults. This hurts them and is their greatest difficulty. Lydia and I had spent time together only that morning with Lydia telling me about her grandchildren. She had reminisced about when her grandchildren used to stay with her and she would look after them when their parents were away. Lydia liked to read them stories and play with them “when they were babies” (AT, RI, Home 1, DRm, Lydia, 22/01/2018). Lydia’s grandchildren no longer visit nor share the significant relationships they experienced as they were growing up. Their lack of connection with their grandmother causes an ongoing deficit in everyone’s life, as they grieve the significant relationships previously shared.

Paul - encouraging stories

Being together and supporting Paul’s voice in his stories and choices is important to Paul’s wife, Bernice. She recognises Paul’s need to communicate his thoughts as she explains:

> *Bernice:…that’s why I come most days so Paul can talk about what’s important to him…He’s always liked people…been in lots of things Lions, School Council...He likes to give…Paul is now way back…He was a sea farer, and sees it in his imagination…the sky is often the sea…he looks at the colouring and he says about bringing ships in because he was a pilot…That’s what the girls [staff] say - every single day he’s bringing the ships in…and he just loves to talk about it…although you can’t understand a lot of it, he does need to talk. It seems he gets it off his chest…I think he'd struggle a lot without talking...*
>
> *Extract 7.33 (AT, RFI, Home 2, DRm, Paul and Wife, 29/06/2018).*

Bernice describes how in words and gestures Paul continues to voice his social identity of giving to others. She recognises and supports Paul when he is living his vivid memories of his sea-faring days in the present. Knowing Paul well, Bernice also gives staff background details about what Paul’s gestures and sounds mean, so they can engage further with him. She recognises Paul’s need to perform his story as a stabilising anchor for his well-being.

In this next extract Bernice admits to not always understanding what Paul says, with fluctuations in his verbal ability. Even so she describes how on the day before, Paul was able to follow her conversation, recognise she overlooked him, and demand to have his voice:

> *Bernice: I can’t always make...although there’s sometimes a sensible…like yesterday I laughed…he was rambling on, and I interrupted him and started talking to my friend…and he elbowed me and said, “Just a minute I haven’t finished!” Just like that and I said, “Did you hear that, Hilda?” That was really strange but he just seemed he didn’t want me to talk… Paul (nodding): Yeh... Bernice: I couldn’t get over that came out of his mouth. Julie: Clear as anything. Bernice: He just elbowed me saying, “I haven't finished yet.” It just made me laugh so much because that*

> *would have been him...“just a minute, let me finish.” Sometimes I think there must be a light in the tunnel that flashes and you know, and then it’s gone. Paul (tone of agreement, raising his eyebrows): Yeh!*
>
> *Extract 7.34 (AT, RFI, Home 2, DRm, Paul and Wife, 29/06/2018).*

The day before, Paul had articulated his agency with strong words and gestures, stopping Bernice speaking over him to her friend. His reaction had surprised and delighted Bernice. On this occasion Paul revealed that he still can express his agency and identity, and not just be a passive and silent spectator to others’ interactions. As Bernice retells this story Paul follows her commentary. He testifies to his right to a place in the conversation, having the last word, “Yeh!”

On another afternoon Bernice raises a query with me in front of Paul, about him eventually telling her to leave whenever she visits him. However, Paul is forthright in responding and demonstrates his agency in his insights and corrections in the next extract:

> *Bernice: I mean there's some days he tells me to go home…You think well okay he’s had enough of me. Maybe something is upsetting, I don't know… Paul (interjects strongly): Sort it out…Instead of going sweet. Well, you saw how much high tide is now. You get it. Bernice: You talking about high tide? Paul: Yeah… Julie: So, in a sense for you to go before there's a high tide maybe… Bernice: Oh yes… Julie: Because I don't want you to miss your bus, or I don't want you to be late home. Bernice: No. Paul (confirming): No, no I don’t blamery (sic)… Julie: For you to be safe and home and in the warmth. Bernice: I suppose yeah, they're looking after you in a way, aren't they?…It's strange what comes from them at times. Paul: Mmm. Bernice: It's nice when it's something you can relate to comes out… Paul: I know I still say that…*
>
> *Extract 7.35 (AT, RFI, Home 2, ARm, Paul and Wife, 13/07/2018)*

Bernice expresses her concern that Paul says, ‘Go home’. Paul shows his awareness and capability in following Bernice’s words. Listening intently, Paul interjects pertinently and clearly. He answers her query, correcting her misunderstandings and giving his reason for telling her to go home. Contrary to Bernice’s view, Paul says, “Sort it out. Don’t go sweet” - proverbial sayings they would both know, meaning she should come to a reasonable understanding. With a nod and direct eye gaze to the horizon beyond the window, Paul draws Bernice’s attention with his gestures and words about the high tide as indicating it is “getting late”. As he lives his past experience vividly in the here and now. As the ship’s captain, Paul would have planned voyages by the tides for the safety of his crew and vessel. Caringly and logically, he reassures Bernice of “no blamery”. But using his familiar language, he wants her to go home safely. I seek to guide and reassure Bernice, as she uses the third person of Paul. Perhaps this is how she refers to Paul now. Or is she trying to assimilate his ongoing capability in caring for her. Nevertheless Paul has the last comment, nodding, “I know I still say that”. Thus Paul voices his continuing authority, expertise, agency and identity, in caring for and understanding his wife in the ways he still knows how and is capable of.

These extracts demonstrate the love and desire these family members had to continue to support the person in their intact capabilities and capacities, while acknowledging their changes and limitations. Through regularly interacting and sharing meaningful relationship with the person, they endeavoured to support their communication of their continuing agency and identity. Yet family members realised such interaction could also be complex and ambiguous, and that they might overlook or incorrectly interpret what the person was communicating to them.

Miriam, Lydia and Paul each revealed that they were able to connect with the content and emotionality of our family interview, by following their relative’s statements, adding their comments, and making their contributions to the conversation. Miriam continued to display her agency and identity in observing and making her comments about others. Lydia followed and augmented her son’s comments with her non-verbal gestures and statements. Paul understood his wife’s concerns and sought to correct them with his gestured and verbal responses. In their responsiveness each person also enacted an empathy and concern, and at times humour, for the feelings and needs of their beloved family member.

7.3 Agency and Identity facilitated by Staff – to be or not Behaviours

Staff facilitation of the person’s agency and identity was a strong theme in many staff interviews. Many considered it an important part of their role. Some suggested that a person’s agency and identity are two sides of the same coin, and that in voicing their choices and preferences in their words and actions they demonstrate their identity and storied-life. This theme also demonstrates that staff differed in their understanding of the notion of behaviours. Some staff interpreted the person’s negative enactments as mostly “behaviours”, resulting from their advanced dementia and not having a specific cause or meaning for the person. Conversely, other staff explained the various ways they support the person’s agency and identity, responding to what they considered was the person expressing or enacting their “reactive responses” to certain precipitating factors at the time. The following extracts in this section illustrate these divergent positions.

Expressing or enacting “reactive responses”

This sub-theme shows that some staff considered the person expresses or enacts their “reactive responses” to certain precipitating factors affecting them at the time. These factors might be emotional distress or physical pain and discomfort.

Mary - supporting her during emotional distress

Carer Mercy looked for the causes and meaning of what she had identified from her previous training as reactive responses. In this next extract Mercy reflects on her broader conception of the person’s ongoing emotional needs and struggles. Mercy describes her approach to caring for Mary when Mary appears agitated or distressed:

> *Mercy: There’s more to behaviours…Keeping an open mind to find out non-verbal cues relating to the person and looking out for these cues is very important…for some listening to their statements. So, I just try to find out. She is angry, lashing out…What is it? Because yesterday her sister came. Mary was talking, and got emotional…But she never said that…I could really feel it. Maybe it's still on her mind...Sometimes when family visits something ticks [the person] off. Because as soon as [her sister] left, - she was…at a loss…eyes really sad and saying, “the next one to go to the grave is me.” Yeah, so I just took her out for a walk, just to wear it off…But it doesn't help. It's so deep in her…She is very emotional and teary…She's a lovely person…Every time I go to her room I make it a point - that oh you interact with me as an adult, okay?*
>
> *Extract 7.36 (AT, SI, Home 2, Passageway, Carer, 12/07/2018).*

Mercy expresses her insight that staff need to keep an open mind by observing the person’s non-verbal cues to gain a broader understanding of their behaviour. Negative behaviours of the person may be their way of voicing ongoing reactions to long-standing, recent or current emotional or psychologically distressing events. Mercy recognises the unresolved deeper issues, trauma and suffering regarding familial conflicts within Mary. These feelings are triggered when her sister visits, as she did the day before. Mercy observes Mary subsequently makes negative reactive responses to other residents and staff. Mercy provides sensitive restorative care by spending time with Mary and listening to her in their garden walk together. Mercy also talks respectfully with Mary during her personal care, to build up her sense of self-worth. Through her attentiveness, empathy, and support, Mercy seeks to provide a space for Mary to voice her emotional pain and experience loving affirmation and a measure of catharsis, comfort, reassurance and peace.

John - recognising his agency and identity

Cleaner Clare also knows John well and shows in this extract that she understands how to relate with him, depending on his mood at the time:

> *Clare: A bit of role play, I think…I know when John first came in, he was lot happier, and in a lot less pain...But most times I can actually relate to him and get him to help. [Mostly] he wants to stand at the breakfast bar and just talk to me and eat his breakfast. Some-times he just hums away. So, I don't force him to do anything he doesn't want to…Yeah, it might be him at a bar where they all get together while*

> *they're racing horses…I can tell when John is getting grizzly. You just watch his hand. If he starts making a fist, okay, I'll leave you alone…He's given everything, now he needs to receive everything…I have done all that training in house… Opened my eyes a little to some people's thoughts…put me in their shoes.*
>
> *Extract 7.37 (AT, SI, Home 2, DRm, Cleaner, 23/07/2018).*

Clare connects John's current enactment of his voice to her knowledge of his storied-life. On this basis she assesses when he wants to relate or needs calming, or even to be left alone, and she appropriates her response accordingly. As Clare often cleans nearby John, they regularly interact. She particularly notices his non-verbal gestures when he appears to be in physical pain or is agitated, and refers him to the nurse. Clare describes her empathic imagination with each person. Her understanding has been enhanced by ongoing training and coaching in dementia care within the organisation. Clare demonstrates her ability to acknowledge John's difficulties, while valuing his unique identity and strengths. I sense in Clare's words that she also receives from John and values their connection.

Several staff referenced the organisation's induction and training. This formation had enhanced their self-awareness, attitudes in upholding personhood, empathy to "walk in the person's shoes", and observation, listening and responsive skills. This training also gave them an opportunity to build their team work as they care for people with advanced dementia. I observed that the attitudes and behaviours of these staff towards people were consistent with their interview accounts. In respecting their personhood and providing responsive care, these staff demonstrated their understanding and promotion of the person's agency and identity, especially when the person was struggling and/or reacting to particular issues. I also observed these staff seeming to work in synch with each other with respect to the person and their attitudes, and approaches to their care.

Leadership coaching and interventions

This sub-theme notes that several leaders identified that some staff issues related to staff defining the person's enactments as "behaviours". These leaders also mentored staff to recognise when the person is expressing or enacting personal characteristics of their agency and identity and how to facilitate the person in this, rather than just assume "behaviours".

John - encouraging his capability

Capability Coordinator Serina highlights the importance of staff learning to recognise the person's agency and identity and encourage their capabilities. In the next extract Serina talks about her approach to coaching staff, and cites the example of John displaying his agency:

> *Serina: We need to change with training…We work strongly with staff explaining…it is actually okay to sit and spend time with that person…a lot of the behaviours are*

> *from ...staff not explaining themselves, rushing the person. They feel they're above that person. I've been here eight years and had no behaviour stuff with anyone… [Staff] ask how do you do it?…You play on their strengths, their capabilities and you do it together. They want to do things themselves, in their time, in their own way. The other week…I helped John with his shower when other staff had difficulty doing this. John knows me. We used to dance together in the singalongs. Someone had said to me, "He's really hard, you won't be able to do him." I said, "Just watch." I came out and they said, "How did you do that?" I said I talked to him all the way through. He was laughing, smiling and let him do his own buttons up and undo them and put them up…Now a lot of people he hits out at. Why? Because we're taking it away from him, and we can't. So, people can't express by talking to us, the only other way is by lashing out.*
>
> *Extract 7.38 (AT, SI, Home 2, Capability Coordinator, 8/08/2018).*

In her role, Capability Coordinator Serina desires that staff change with training and realise the importance of interacting with people. She notes that people with advanced dementia respond negatively to some staff who, due to lack of training and skills, try to control them during activities of daily living. In contrast Serina is alongside John. They share a close relationship and her description of John's personal care seems to be a metaphor of a relaxed synchronised dance together. Serina says they have often danced together during concerts. So Serina affirms John's personhood, drawing on his strength and trust, encouraging his capabilities and participation. Together they perform the paradox of remaining close while giving John the floor to take the lead and voice his agency and independent identity. Therefore, with Serina's facilitation, she and John have an enjoyable interactive experience, with John laughing and smiling.

The Residential Services Managers (RSMs) both talk of responding in a timely manner to conflicts and incidents occurring between residents, and between residents and staff. They ascertain the causes of incidents and address them to prevent similar episodes happening. RSM Ruth explains in this next extract how she manages these incidents and what she discerns:

> *Ruth: Yeah, because I get the incident reports from the staff that have been grabbed, scratched, spat at…Often when I get the person in here going through how it actually happened it's because of being quick or wanting to do something the person's not ready for...I'm sure our care staff have said to you that they wish they had more time to be slower and easier with people. I wished we had the money to be able to do it as well. But yeah, it's a matter of being self-aware of how they can do things better and putting this into practice...*
>
> *Extract 7.39 (AT, SI No. 3, Home 2, Office, RSM, 16/02/2018).*

While not wanting to generalise, RSM Ruth has identified a pattern within incidents of the person's negative behaviours towards staff. Staff imply to the RSM in their debriefing interview their task-focused or out-pacing behaviour, and not listening or explaining to the person. She counsels staff to become self-aware, to alter their behaviours and explain their actions so they support each person's agency, identity and actions accordingly. Both RSMs comment on valuing the organisation's ongoing training and mentoring of staff. This programme develops staff values, attitudes and self-awareness in personhood, skills in understanding the language of people, and person and relationship-centred care, specifically with people with advanced dementia.

In both homes the RSMs describe how the multi-disciplinary leadership team (see Glossary) meet regularly to discuss each person's specific needs and issues. Together the team discerns and implements facilitative strategies to support each person holistically. These interventions encourage each person's voice in their agency and identity and promote their well-being. Several staff highlighted to me the person's appreciation in participating in these activities, and that they helped maintain the person's positive engagement and prevent conflict and distress. Examples of such interventions included: participation in a quiet late afternoon activity for Luke, Philip and others (Extract 7.13); a one-to-one garden walk and conversation with Mary (Extract 7.34); and during his personal care recognising John's agency and capabilities (Extract 7.36).

Staff promoting the person's agency and identity

Staff members in various roles spoke of how they appropriated their care to promoting the person's agency and identity. Housekeeping Manager Elise is attentive to the dining experience being positive, as she describes in the next extract:

> *Elise: We need to recognise the significance of sharing in eating meals as part of the person's identity and history…I am present during mealtimes to observe…from their expressions, their actions regarding the meal, whether they eat; come and go quickly. Placement of residents is very important, according to their preferences and capacities to relate or be silent. If there is an issue we get onto what is happening immediately and seek to resolve it.*
>
> *Extract 7.40 (AT, SI, Home 1, Housekeeping Manager, 17/11/2017)*

Elise emphasises the need to be attentive to the important rituals around dining experiences, to make them pleasurable and participatory for each person. The person's verbal and non-verbal language express their preferences and responses to this experience. If there is disengagement the manager considers possible causes and immediately addresses issues. Ensuring engagement in this experience facilitates social interaction and a relaxed atmosphere, promoting each person's nutrition and well-being.

In this extract Laundry Person Kristie describes shaping her praxis to each person's choices:

> *Kristie: A part is taking their laundry back, having that contact with them, particularly the women. It means a lot to them I've got care of their washing…Sometimes it takes a while to work out what they need or want…on how they react to me…putting it on the bed or away in their wardrobe…they'll give a gesture that usually shows me what they want me to do.*
>
> *Extract 7.41 (AT, SI, Home 1, Laundry Person, 26/02/2018).*

Kristie acknowledges that laundering the person's clothes is a significant act as part of their history and identity. She recognises that the woman's role particularly has often been shaped as a home-maker, including laundry tasks. Clothes continue to be an aspect of the person's identity and outward appearance, so the person needs to retain some control and agency in its care. Kristie interacts with each person, attentive to their choices and requests, expressed according to their voice repertoire.

I ask Enrolled Nurse Aggie how she responds when a person is enacting their needs and concerns and she gives her considered response:

> *Aggie: They obviously want something, words but jumbled, so you have to decipher through process of elimination…it's time consuming… a process of working out physically where they are and what they might want…difficult and some may get agitated and physical, because they can't get through…One particular gentleman, Luke…he wants something but can't say that…So you have to put yourself in their shoes, and work out what they might be getting frustrated about…try and just reassure him…and say, "That's what we are here for, you ask if you want anything". Julie: How do you manage that? Aggie: Frustrating at times (laugh)…Most of the time I guess you sort it out, do that process…You want that outcome to be positive for that person ...*
>
> *Extract 7.42 (AT, SI, Home 1, Nurse, 18/12/2017).*

Aggie describes the challenges to understanding the person's needs expressed in jumbled words and gestures. She describes her self-awareness in the empathy, time and effort she provides. This enrolled nurse endeavours to adapt to the person's changing communicative ability and alleviate their frustration. She moderates her own frustration in trying to understand and communicate reassuringly with the person to achieve a positive outcome of accurately assessing their needs and providing appropriate care. According to Aggie and other nurses, this is an exacting but necessary attitude and intuitive process in the care of the person.

The following extracts demonstrate how various staff members and teams practically supported the agency and identity of the person, as exemplified by Thomas and Miriam.

Thomas - art space for solitude and pleasure

The lifestyle coordinator and assistants have responded to Thomas’ artistic and solitary needs by providing him with his own art place. Here Thomas can be absorbed in his artwork (AT, SI No. 2, Home 1, Lifestyle Coordinator Prue, 8/01/2018). Thomas’ possessive and competitive nature is challenging in the communal setting. Careful recognition and support of Thomas’ underlying needs are crucial. In the following extract, Thomas’ daughter Cynthia explains her father’s reactions:

> *Cynthia: With men Dad has always been competitive… Dad, always the biggest and the best…what he’s saying now…I was so happy Prue and the team organised a space for him… and made a huge difference to him…See Dad’s painted all his life.*
>
> *Extract 7.43 (AT, FI, Home 1, Chapel, Thomas’ Daughter, 4/02/2018).*

Thomas’ conflictual relations with men are historical, rather than attributable to his advanced dementia. Thomas’ daughter values that the special art space has creatively met several of Thomas’ needs. Here Thomas experiences meaning and purpose, solitude and peace, and expresses his voice in his artwork.

Miriam - attending to her appearance

For many people their appearance is a significant aspect of their continuing identity, and was particularly observed as important for Miriam. When Capability Assistant Joylene comes to get Miriam to collect the lunch trolley together, she affirms Miriam’s appearance and Carer Jill joins in:

> *Joylene: Where is my lovely Miriam?… Jill (proudly as they surround Miriam): I dressed her today beautifully…I think this should be the outfit for the next concert. (to Miriam): Where’s your diamonds?… Miriam: Where’s me diamonds? (Miriam holds up her rings on her fingers and beads around her neck) Jill: Oh there they are!*
>
> *Extract 7.44 (AT, GI, Home 2, Passageway, Miriam, 6/07/2018).*

I observe Miriam’s responsiveness in being affirmed, as I note later:

> *With awareness, Miriam receives a staff member’s positive comment about her appearance with a smile. Relating with familiar staff seems to lift Miriam’s spirit. As they attend to and affirm her appearance staff encourage Miriam to express herself and enjoy her day.*
>
> *Extract 7.45 (POD, Book 2, 6/07/2018).*

Staff support Miriam in helping her look and feel attractive. Miriam definitively resists being over-looked and values being complimented (RJ, Book 2, 3/8/2018, 6/07/2018; RCP- Miriam). Thus Miriam enacts her agency to promote acknowledgement of important aspects of her identity by others (Ward, Campbell & Keady 2016).

In performing their role responsibilities most staff members endeavoured to recognise each person's agency in their choices and preferences and preserved identity, and appropriated their care accordingly. They interacted with each person in various daily matters and activities, responding to each person's needs expressed verbally or in their embodied gestures. The examples of Thomas and Miriam showed how staff were responsive to their individual voices and provided for their unique needs with particular care and interventions. The atmosphere was mostly amiable and relaxed with staff seeking to remain calm and attentive to each person. Respecting and supporting the person in their agency and identity depended upon also knowing and valuing the person's storied-life.

7.4 Voice Through Sharing Storied-life

The person's storied-life is unique to them and continues to be a significant part of their present life. Their storied-life affects the ways in which the person expresses and enacts their agency and identity in the present. This overarching theme has four sub-themes demonstrated in the ways in which people expressed or enacted their storied-life: as converging the past with the present; as enacting a past ordeal; as past story resonating with present story; and as reminiscence.

Story converging the past with the present

This sub-theme shows that for some people their past story was embodied so vividly in the present that they were actually living the past in the present, as was Paul's situation.

Paul

As I listen to Paul I too become included in enacting Paul's long descriptive story, as together we look through the window to the horizon of the sky:

> *Paul (Looking out, pointing): Still got the sinker out there? Julie (looking out in that direction): Not sure and the weather's bright blue sky but a cold frosty morning. Paul: Yes, sure is! Julie: Part of your job as captain watching the weather. Paul (laughing heartily): When it decides where it's going…Last night actually we were up now the dove of the Murray, sitting by the brae… Julie: sitting by the river with your hands. Paul: Yeh for sure… Julie: Wow. What was it like? Paul (pushing his hand along on the side flattened): Cccccccccccrrrrrrrrrrrrr. Yep! Oh we went... Julie: Was the water cold? Paul: Yes! … uhum Something…it's make… (He points out the window) Julie: What's out there? Paul: Mmmm…I'll call you now and then… Julie:*

> *OK (as Paul chuckles)… (Paul makes a sound like whistling till it seems to land)… (strong tone but quiet voice): See I got it… Paul (as he looks closely): My ship there…Yeh (nods and moves his hand across all he can see). Julie: Yes, very good… Paul: But we had family…*
>
> *Extract 7.46 (AT, RI, Home 2, DRm, Paul, 2/07/2018).*

Paul responds to my attentive listening and imaginative engagement with his intact sense of humour and extended verbal and non-verbal story-telling. He uses descriptive words, sounds and gesturing of both his face and body. He uses the present tense to describe what he sees and responds with the present when I use the past tense. Soon I discern that Paul's past history is the scene he actually sees, hears and experiences bodily before him now. His ongoing capability in performing his lived experience seems both important and instinctive, and seems to enliven him. His story affirms his identity and what is most important to him in the present. He stops at his apparently significant comment about his family.

Paul exemplifies that reminiscence is not just about remembering the past, but also about living his history existentially.

Story enacting past ordeal

In contrast the person may perform in their words and non-verbal language some past emotionally difficult story or ordeal to an attentive listener with whom they have a trusting relationship, as demonstrated in the next extract.

Philip

In the late afternoon Philip and Luke regularly sit together near the entrance, watching people passing and greeting those who acknowledge them. I join them and Luke sits quietly as Philip talks fervently, seeming to recall an experience from his jockey days:

> *Philip: I'm saying I'm jumping over tyres at the end of the… Julie: Oh, OK. Philip: Only thing I could do...after that, 98, 97 Julie: Wow! Philip: Had the horses… Julie: OK! Philip: They say...that's how it is…through the side, side…I don't know…Tell her…either have to sell it or... Julie: What do you think? Philip: I'd sooner take the peri posi No you can't… Julie: True… Philip: And so are these people races raises on the (Philip continues non-stop voicing his story to me)…Oh yes! there was a fire…this time they asked me to put it in my…horse…so that's why…and I think of you and I know you've got things to do as well and to try and work out how in the hell to do…(Eventually Philip quietens and after a time I say)…Julie: I'll leave you to it. Philip: Thanks for listening to me. Julie: Oh that's alright. Philip: You know where the other wire is? (chuckles) Julie: No I don't know where the wire is…but I'm sure*

> *it's not too far away. Philip (bursts out laughing): Oh God. That's the best night of the day. (We laugh together). You can come with me anytime, you can… Julie: Alright. I'll leave you to it now. Philip: Yes. Thank you very much.*
>
> *Extract 7.47 (AT, RI, Home 1, Passageway, Philip, 15/01/2018).*

Philip is storytelling as I listen to his lengthy account. I "collaborate" in being attentive and coalescing with him in my responses, providing querying and resonating sounds and words encouraging him to continue (Hydén 2013, p. 360). Philip's story appears traumatic, judging by the urgency of his body language, grimacing and words. When he concludes his story, Philip becomes quiet and still. Although I have little understanding of his story's content or meaning, he appears relieved. Philip articulates in a clear sentence, his gratitude that I have listened to him in recounting what has been apparently a very tough experience. His telling of his traumatic story to me has mattered to Philip.

Past story resonating with present story - Philip continues

The deep emotional content of Philip's venting through the laboured performance of his story becomes more apparent to me later, when sitting with Philip and his wife Phoebe.

On this occasion Phoebe tells me of the beginnings of their relationship way back before their marriage. She speaks of Philip's traumatic accident:

> *Phoebe: When I first met him, he was a hurdle jockey…going over the fences…just fantastic…And I was working in the city and I said to the barman, "My boyfriend's riding in the first race at Pt Augusta. Tell me how he goes." I saw him later and asked him. Laughing he said, "He fell off at the first fence. I think he's gone to hospital", and he was. After that he gave up and went off to study accountancy…*
>
> *Extract 7.48 (AT, RFI, Home 1, Café-Courtyard, Philip and Wife, 3/03/2018).*

The story Philip had performed to Luke and I previously (see Extract 7.47 above), seems to have been this event of earlier injury and trauma, resulting in Philip giving up his hope of becoming a jockey. Consequently, his life completely changed and this event seems to have remained embodied in him (AT, RFI, Home 1, Café-Courtyard, Philip and Wife, 3/03/2018). Phoebe then portrays their current trauma vividly:

> *Phoebe: Yes, he came here in late September…And he wasn't well. He had a nasty cough because he came from hospital…I mean [Philip] has been suffering for several years. I always imagined we'd live together happily. We'd go to the movies and every morning we'd go for a coffee Philip: Mmm, yes… Phoebe: At Mick's coffee shop. They would all greet him "Hello, [Philip]!" (Philip laughs) It was lovely!*

> *And when he got sick…(Phoebe is crying) I was sick at the same time. So the kids arranged all this. The doctors said he won't be able to go home…I think the first 2 or 3 months I was just grieving.*
>
> *Extract 7.49 (AT, RFI, Home 1, Café-Courtyard, Philip and Wife, 3/03/2018).*

Phoebe explains that Philip and her, along with their family, have been living in crisis-mode for several months. Phoebe had thought life would continue on happily, in being together at home and in their local community, despite Philip's advanced dementia. But massive change began with the trauma of Philip suddenly becoming very sick and going to hospital. He was unable to see Phoebe, who also was sick. This necessitated him moving into residential care. As I listen I realise that Philip's previous earlier traumatic story resonates with their present traumatic crisis. Perhaps in telling his past story to me Philip was trying to work through his current loss and grief, and seek some meaning and/or resolution. Suddenly their life together had traumatically altered with Phoebe and Philip being separated, and it would never be the same again. I later reflect that Philip calling for Phoebe each afternoon indicates the traumatic loss he still experiences. Philip's deep sharing with me seems born of our being alongside each other and developing a trusting relationship over time (RJ, Book 1, 3/03/2018).

I reflexively recognise later the significance of being a facilitating companion as the person moves in and begins to settle in the home. In times of existential trauma a person may reminisce about a previous traumatic event in their life.

Story as reminiscence

This sub-theme shows that the person may reminisce regarding their storied-life, in response to familiar activities like singalongs with favourite songs, craft in making home-made items, and church services reminding the person of Sunday School and church choirs. These activities intentionally promote the person's voicing of their reminiscence when facilitated by Lifestyle or Capability staff or the Chaplain with Volunteers, or perhaps a singer or minister. In providing such opportunities the person interacts with others and relationships are deepened.

Staff demonstrate how they also play a facilitating role by knowing important aspects of the person's storied-life that define their continuing identity. They relate meaningfully with the person regarding these aspects of their story. Carer Roy describes how he gets to know people and their story in the next extract:

> *Roy: I try to get to know them as people, to ask them what they used to do, where they lived. If I see family members, I try to find out. So, if I see family members I usually ask them. I don't become overbearing and ask them too much. But I like to ask a little bit, what they used to do, where they lived. Just get a bit of an idea of the*

> *environment they lived in and their working life, what they sort of did…that helps me because then I can converse and reminisce with them…if you mention something they have experienced, they light up their smile. They recognise you understand.*
>
> *Extract 7.50 (AT, SI, Home 2, Carer, 7/08/2018).*

This extract demonstrates how some staff recognise the importance of knowing the person's history in interacting with them and their family. This knowledge assists staff in understanding the person's agency and identity in the present and interacting with them on relevant topics. It also encourages rapport in developing and deepening relationships and supporting the person to enact their voice. However, such knowledge varies across staff. For example, one carer tells me she does not have time to read the person's social-spiritual care plan, nor talk with families. I wonder later whether she is unable to easily access the person's care plan during her busy shift. She may also lack confidence in relating with family members. I observe several staff do not seem to interact with people, and in our conversations do not know details about each person. On the contrary, other staff can give a detailed account of many people's storied-lives (POD, Book 2, 3/07/2018).

Miriam - continuing to sing and dance

Miriam enacts an important aspect of her storied-life in her singing and dancing. At the weekly concert Miriam takes centre stage and interacts with other residents with whom she has relationships. I later note my observations of Miriam's participation:

> *Miriam enjoys the weekly concerts in the activity room. She remembers the words of well-known songs and sings along. Not at all self-conscious Miriam breaks into graceful dance moves around the room with capability assistant, Joylene, whenever she hears familiar music (OG- Miriam). She stands behind a friend and tousles their hair. At the end of one of the songs Miriam stands in front of the performer with arms outstretched and proclaims to the audience of residents, "There you are; we got to the end of the song." I note that this is one time when as a performer Miriam interacts with other people.*
>
> *Extract 7.51 (POD, Book 2, GA, Home 2, ARm, Miriam, 11/07/2018).*

Miriam's daughter Lynette informs me that her mother's life-long love of singing and dancing prompts her enthusiastic vocal response now. Her dance moves are reminiscent of her husband and her leading the old-time dances in local community halls. Her freedom of expression in this context and with others is transformed by her engagement with the music and her dance moves. Reminiscence about past experiences may be stimulated in times of being together. Activities such as music and craft may prompt the recalling of stories in verbal and non-verbal form.

7.5 Summary

In this chapter I have presented the findings of how the person expressed and/or enacted their voice in relationships with others in four major ways: within organised places and activities that became spaces promoting people’s voices and relationships; in expressing and/or enacting their agency and identity; by being encouraged by family and facilitated by staff; and in sharing their storied-life in various ways.

This chapter has shown how intentionally arranged places and activities provided spaces prompting the person’s voice in interaction and relationships. Staff regularly positioned people in comfort chairs with others who chose to congregate together in carefully arranged chairs in various places. Many people demonstrated their continuing need to be with others, interact and be in relationships one-to-one and in groups. Several people continued to display recognition when a person was struggling, providing support to them with empathy and care. Various activity groups facilitated by staff catered for the diverse needs and interests of participants, encouraging their interaction and development of relationships. On the other hand, some people preferred to spend the majority of their time in solitude, wherein their needs to express and enact themself were provided for by staff. For each person their preferred ways to spend their day seemed to affirm their sense of self, meaning, purpose, and well-being, confirmed in their comments and gestures.

In this chapter the findings have demonstrated that the person expressed or enacted their personal characteristics of their agency and identity through their critique, and in their personality traits and rituals. Several staff in various roles considered a significant part of their role as facilitating the person’s voice. Many staff stated they performed their responsibilities in accordance with the person’s choices, preferences and individuality. Personal and group activities encouraged the person’s agency and affirmed their identity, in using their capabilities and capacities. Multi-disciplinary planning and implementing of interventions were tailored to the person’s needs, identity and storied-life. These practices enhanced the person’s demeanour as they engaged with confidence and pleasure in meaningful activities through their day. Conversely, the person reacted and critiqued staff members who were controlling, rushing or task-oriented, rather than interactive with them. Managers trained and coached staff to be self-aware, recognise personhood, and be person and relationship-centred, in order to promote the person’s agency and identity. Some staff recognised when a person’s negative reactions towards them and other residents were triggered by distressful events, difficult relationships or inner pain, and provided responsive empathic care.

Many staff gained knowledge of the person’s storied-life to guide them in becoming a facilitating companion in interacting and being in relationship with them. The person was able to enact or express something of their storied-life in various ways with their voice repertoire. The sharing of their story became a testimony to who and what had been and continued to be significant to the person. This overarching theme demonstrated four ways in which people expressed or enacted their storied-life: as converging the past with the present; as enacting a past ordeal; as past story resonating with present story; and as reminiscence. Some family members spoke of supporting their relative to maintain their capability and capacity to interact. In doing so, family encouraged their relative to express or enact their agency, identity and storied-life. Several people participated in the interview with their family member and demonstrated their ability to follow the conversation, and aptly gave their verbal and/or gestured input.

As relationships continued to develop, they would also deepen. Chapter 8 shows how and why, within these deeper relationships, the person expressed and/or enacted their voice in connecting to who and what was important to them. In trusting and attentive relationships, the person testifies to the difficult and also significant aspects of their lived experience, signifying their spiritual dimension, in their last phase of life.

CHAPTER 8 VOICE IN DEEPENED RELATIONSHIP

Introduction

The first two chapters of analysis and findings considered how in the forming of relationships (Chapter 6), and in the developing of relationships (Chapter 7), the person expressed or enacted their voice. This chapter presents how as relationships have deepened with myself as researcher and with others, people expressed their deeper feelings and concerns. In this chapter I also explore how, through their voice, the person formed deeper connections with those people and aspects of their life important to them, as expressive of their spirituality.

This chapter is structured around the four themes of the person's expressions and/or enactments of their voice in the deepened relationship. These are 8.1 'Voice supported by Trust and Attentiveness', which considers the relational support by staff of the person; 8.2 'Voice expressing Grief and Loss'; 8.3 'Voice making Deeper Connections'; 8.4 'Voice making Last Testament'.

The following section considers how, in displaying trustworthiness and attentiveness, staff members built relationship with the person over time and encouraged the person's voice.

8.1 Voice Supported by Trustworthiness and Attentiveness

This theme identifies that many staff considered trust and attentiveness essential qualities in the caring relationship. These qualities deepen the staff member's empathy with the person and their understanding of the person's communication of their needs and concerns.

Enrolled Nurse Aggie emphasises the necessity of staff developing trusting relationships:

> *Aggie: They're not people you're just going to say, "put on this"…You need to understand this person is an individual...It's very personal care we give…a bit daunting for some that you need someone to help you...So, you need to have a pretty good relationship to say I'm here for you, don't hesitate to ask, I'm happy to do it…and the relationship is built on trust.*
>
> *Extract 8.1 (AT, SI, Home 1, Nurse, 18/12/2017).*

Aggie explains that staff members are not just doing a job, nor is it about controlling the person and telling them what to do. In this care, staff must build the person's trust in facilitating them to do the things they had once done for themselves. This means being available, attentive and willing to respond to the person in whatever ways they need. The person then responds positively in their intimate care.

Carer Mercy explains this trustworthy relationship further, by describing Mary's personal care:

> *Mercy: Whatever happens to your brain…The real inner stuff remains the same. That's the biggest insight I have found - the core person as the soul...Even though they have severe dementia…our brain has windows of clarity…Deep within their soul, yeah. You have to feel it otherwise you'll be always in trouble. They'll be unhappy, it shows. Julie: So it's a deeply spiritual thing? Mercy: Yeah…you know why? Mary doesn't like the sweet talk. Julie: No? Mercy: You straight away come to the point. We are showering you. That's it. "You're calling me smelly, that's not too good." I said, "Oh, it's good that I'm telling you not in the common place," and Mary laughs. She likes that... Julie: Her finely tuned humour, isn't it? Mercy: "Oh, I can see now," she says. She just goes in. She is showered. So much there inside her. You follow those cues. It's very comfortable for her and everything gets done nice and smooth. Then she tells me you really know how to dress me. That kind of intimacy, and she just felt so. She applies lipstick and she wants to put that jewellery on, and she is really with it, okay? To me that's how it comes up...that's enough.*
>
> *Extract 8.2 (AT, SI, Home 2, Carer, 12/07/2018).*

Mercy reflects that the person's ongoing core, their soul's expression continues to be responsive, regardless of their cognitive changes. She describes how she and other staff also need to feel this care deeply within themselves, in their core as a spiritual experience, or the person will not make the connection with them. Mercy describes the need to understand each person's unique personality traits and to mirror their ways of relating. She describes her approach to facilitating Mary's personal care and her resultant deeper kinship with Mary (Heshusius 1994). Thereby Mercy encourages Mary to participate in her personal care with trust, openness and pleasure. In response Mary's sense of self-worth lifts. She desires to be pampered and for her embodied beauty to be enhanced with lipstick and jewellery. Mercy's empathy and understanding enable her to enter imaginatively and practically into Mary's experience of making her glamorous.

Carer Annabelle explains the practical implications of being trustworthy and attentive:

> *Annabelle: But we must listen to what they say…aware, observe and be careful. We need to ensure they hear us and see us…Some staff don't really listen, just goes over their heads. The residents know that if I say I'm going to do it that I will. I always go back to do what I said I would do. That means that I am trustworthy and reliable. Some residents' trust has been broken. It does matter that you don't walk in with chips on your shoulders. We all have times but we must leave them at the door.*
>
> *Extract 8.3 (AT, SI, PhI, Home 1, Carer, 5/03/18).*

Annabelle articulates the essential attributes she seeks to exercise in the person's care, those of listening, observation, awareness, and attentiveness. She seeks to be consistently trustworthy and reliable in her words and actions. Her observation is that if the person encounters a staff member who is inattentive or unreliable towards them, they reciprocate by not trusting them. Staff attitudes affect the person's capacity and willingness to voice their needs and choices, even when they are capable of doing so. Lifestyle Assistant Bonnie also identifies the self-awareness of staff regarding their attributes and attitudes as a significant factor in being trustworthy and attuned to the person:

> *Bonnie: My level of awareness and sensitivity at the time will help determine how I find what their need is and interpret what they're saying… Julie: How do you prepare yourself for that? Bonnie: Moment by moment because I've come to know each person…if I see them coming then I'm preparing without realising…to receive from them. I think we all do that. If I see he's really frustrated I would with more sensitivity...spend that extra moment with him (rising speech tension). It takes more time. Time and the demands mean I can't always have those extra moments, and that can be frustrating for me. I like to spend extra moments. And I do when I can. But we do what we can…*
>
> *Extract 8.4 (AT, SI, Home 1, Café, Lifestyle Assistant*, *1/12/2017).*

Bonnie articulates that the attitudes and awareness of staff members affects their responsiveness to the person at the time. Bonnie replies honestly that her and others' level of sensitivity and receptivity to the person may vary, dependent on how the staff member is going personally, and also their immediate work schedule demands. Bonnie's voice tone indicates that she feels the tension at times when the person needs more time, and her time is limited. Nevertheless, Bonnie endeavours to be attentive in each encounter, to discern the person's needs and respond as she is able. Bonnie emphasises that knowing the person guides her in becoming receptive in each encounter and attuned to what the person may voice.

The practical implications of trusting relationship are exemplified in this next extract, when Carer Mercy describes walking with Mary who is then encouraged to attend the concert:

> *Mercy: One day there was a concert in the hall, people were walking down…So, I said I'll take you down. Mary got tired and we made her sit somewhere and I told her, "Okay I'll come back. It's not yet begun and so we still have time"... I went back to help another lady. In the meantime Joylene came to take Mary…She says, "No I'm not going anywhere. My sister is coming"…She took it really personally and she was waiting and waiting. Julie: Oh, waiting for you? Mercy: Yeh. Then Joylene rang me, "you have to come back". I came back from my car park and took her there. "Where did you go?", she said.*
>
> *Extract 8.5 (AT, SI, Home 2, Carer, 12/07/2018).*

Mary is willing to go to the concert because she trusts Mercy to walk alongside her. Mary voices to Joylene her need for only Mercy, “my sister”, as Mercy has promised. Mercy, still nearby, realises she must return to Mary. The building of trust as a feature of the relationship between Mary and Mercy is especially significant as Mary’s familial relationships are fractured. Mary identifies Mercy as “family” (Extract 7.33) In her mutual response Mercy seeks to be trustworthy and attentive towards Mary.

Aggie, Annabelle, Bonnie and Mercy each stated the importance of being trustworthy and attentive as fundamental to their caring role, to enable deeper rapport and understanding in their relationship with each person. I observed that trusting relationships between the person and staff happened over time, as staff were attentive and intentional in developing relationships. Such relationships are necessary, according to Nurse Aggie, because the care is intimate and person-centred and the person’s agency is crucial. Lifestyle Bonnie highlighted that trust requires self-awareness and sensitivity. For Carer Annabelle this involved attentive listening, being careful and reliable to the person. Carer Mercy recognised that her trustworthy and open relationship with Mary encouraged Mary’s self-esteem and ability to voice her pleasure and display her beauty, and to interact more confidently.

This section has described the views of staff regarding the importance of trust and attentiveness to those they care for. These qualities encourage the development and deepening of relationships, and the person’s confidence in expressing their needs and choices. The next section demonstrates how the development of trust and openness, in this instance with myself as the researcher, enabled the person to express very personal feelings of grief and loss.

8.2 Voice Expressing Fears, Grief and Loss

This section demonstrates that when relationships deepen with trust and attentiveness, the person may feel supported to share their inner experiences of self. Connecting in relationship became a place where several people displayed trust and openness, sometimes expressing their deeper emotions and needs to me. As I sat with Luke, Sarah, or Lydia, in conversation each of them periodically voiced their deeper emotions in their lived experience of grief and loss.

Luke - grieving loss of ability

Luke shares with me issues of changes and losses within himself that are distressing and causing him grief, as portrayed in the next extract. I sit down with Luke one afternoon at the Chapel entrance. Immediately he speaks of his loss of memory and his confusion:

> *Luke: But I can’t remember, terrible, isn’t it? Julie: Oooooh! Does that frustrate you? Luke: For this one, yes, he did. But he doesn’t know what he’s doing…I don’t know how to mish it up, and I should do. I’ll have to do better. Julie: Ooooh you do the*

> *best you can, Luke… Luke:…I'm not doing good. It's awful. Julie: Is it, I'm sorry. Luke:…See I can't use it (he turns over his empty cup)…you should like everything, shouldn't you?... Julie: well, I thought it is nice to sit with you and just talk. So, thank you. Luke: Oh right (Luke grimaces). Julie: You find that a bit surprising? Luke: yes, a little bit. Julie:…I think you're good company... Luke: Yeh. I try to be. But you can't get it with everybody. I don't know what I'm doing with myself…That's the trouble.*
>
> *Extract 8.6 (AT, RI, Home 1, Chapel, Luke, 29/01/2018).*

Luke uses the third person, implying himself, when discussing the mounting confusion and discomfort in his head. This is his way of referring himself. He apparently may be distancing himself from his acute physical and existential pain in these moments of insight. Metaphor and sayings are a way Luke expresses his emotional-spiritual state. Luke articulates his lived experience negatively at times. For example, he says "We've come to a dead end" (POD, Book 1, 1/12/2017), and turning over his empty cup, says "I can't use it". These seem to be metaphors for his inner turmoil. He intimates shame that he is unable to "mish it up", perhaps he feels he cannot work it our or understand what's going n inside him. Luke now trusts me to talk about his "awful" struggle. I affirm Luke's continuing value and capability despite his challenges.

Various staff including Bindy, Anthea and Bonnie have close relationships with Luke. They listen and support him and also each other with empathy, concerning Luke's decline (AT, SI, Home 1, Café, Carer, 27/11/2017).

Sarah - grieving loss of homeplace

Another deepening relationship for me was with Sarah. One morning as we sit together Sarah expresses her experience of grief regarding her sense of loss of no longer living in her beloved hometown, and her perplexing emotions when imagining being there:

> *Sarah: We went through to Boga…saw the garden…walked through it… Julie: And I hear you grew up there. Sarah: in the hospital at My town... Julie: I've been there, lovely place. Sarah: Beautiful, all those trees… Julie: And when you say "My town" you smile… Sarah: Happy, you're home again. Amazing, a long while after being in My town,…I can't believe even being there… Julie: So that's home for you, a good place… Sarah: Well, it's always been home for me…I never went there afterwards. I often thought a little wish but no one asked me, and I wanted that…so, I was little broken about that. I thought to myself it was so nice, been mine, but it never came to me…and I often wondered if I did the wrong thing there...I try to keep most of it quiet, what I do. So, I just got back to the main street in My town, up the avenue...I got quite a tickle standing under those trees…A few people wanted to speak to me but (Sarah uses her hands to gesture no) not my part…We didn't say a lot. Some-*

> *how we understood each other…(protracted silence). Julie (eventually): Well, it's lovely having a chat with you. Thank you, Sarah. Sarah: Where is it? (looking on her arm for her watch). Julie: There … on your wrist. Sarah: That's all I have now. I don't think I'll ever have a big one.*
>
> *Extract 8.7 (AT, RI, Home 2, DRm, Sarah, 5/07/2018).*

Sarah demonstrates her ability to articulate clearly her complex and contrasting emotions about feeling happy to again return to her hometown in her imagination, in depicting its nature and beauty. But then she reveals, "a little broken" that she never went back, wasn't asked, and still wonders why not. I sense her ongoing grief with associated regret. Sarah even seems to also experience some residual shame that she might have done something wrong. I feel her deep trust in me in telling her story. In the latter part it seems Sarah actually returned to walk in those streets again, albeit in her imagination, since it was "not [her] part" [home?] anymore. Eventually her comments about her watch perhaps indicate she can expect nothing more, or that time moves on and even ends, or she is refocusing on the present time away from reminiscing with me. Sarah reveals much about herself and her grief as well as her resilient acceptance (POD, Book 2, 5/07/2018).

The next day, Sarah, Carer Janice and I are together as Sarah again talks about her storied-life in her hometown. But I sense she talks with less sadness, as she smiles (POD, Book 2, 6/07/2018).

> *Sarah: It all depends whether they come back out of the garden. We often used to have a lot of fun you know. Julie: Oh really? What did you do in the garden? Sarah: Just a difference there. Julie: Yeh. Do you love the garden, Sarah? Sarah: Oh yeh. I do. A whole lot put together. Julie: Oh how lovely. Sarah: Then you go into the other garden. (She looks out to the courtyard) Julie: It's beautiful out there isn't it? Sarah: Yeh, that's right. Julie: Do you sit out there when it's hot. Sarah: Yes, I do. It's ideal there. And the garden right on top of it. Julie: Yeh. Sarah: We move around it you know. Julie: How lovely! Sarah: It's really beautiful…and it's touched into [hometown].*
>
> *Extract 8.8 (AT, RI, Home 2, DRm, Sarah, 6/07/2018).*

On this occasion Sarah uses extensive descriptions and place names about her hometown. Sarah is her most coherent this time, giving her story positive meaning. Perhaps she is having a happy day, and she joins her past story of her hometown with the sunlit garden she enjoys outside the dining room. But my sense is also that through voicing her story to attentive and empathic listeners, its burden has been released from within. Sarah now can appreciate some aspects of her storied-life as more resolved positive memories (POD, Book 2, 25/07/2018).

Lydia - grieving loss of partner

Lydia also demonstrates her awareness of feelings of grief and loss. She sometimes talks with me about her husband who has died, and looking for or missing him greatly:

> *Lydia: Yesterday I was talking to my husband. And today I like this and this (acting out looking in every direction). Julie: You were looking everywhere. Lydia: Did you find him? Julie: No, I didn't. I'm sorry, Lydia. Do you miss him when he's not here? Lydia: Yes, what can I do? He should be here…This morning I see him…but he's not here. Now that I know he's here I can give it to him (the napkin). Last night I talk with him but not a lot. He's not dead? Julie:…I think he has passed away. Lydia: Would you like to cut another piece? Julie: Of your napkin. You want to share a piece of that napkin with me?…You have it. Lydia: Alright. (Lydia crosses herself.) He is here because I saw him passing. He likes those. Julie: He likes bread? Oh. Lydia: My husband is here. Look in the back.*
>
> *Extract 8.9 (AT, RI, Home 1, DRm, Lydia 22/01/2018).*

Lydia voices her lived experience of talking with her husband and her distress in trying to locate him on this day. Her emotions vary, depending on whether she feels she has seen him or not. Her inability to sequence what is past or present and what is actual with her hopes and imaginings, make this all the more confusing for her. She wonders and queries if he has died, and I confirm this gently. In tearing her napkin she seems to signify the sacred ritual of sharing communion bread in the funeral mass. Crossing herself perhaps signifies her understanding and his commemoration. Lydia's grief and loss continue to be complicated as she moves between believing her husband is still with her and talking with him at times, looking for him everywhere, and wondering if he has died. In their interview, some staff tell me they sit with Lydia and others as they express their continuing sadness at the loss of a loved one. Several staff considered that a person's sadness would recede as their dementia becomes more advanced. On the contrary, I encountered several people who experienced ongoing fears, grief and loss, and needed attentive support in expressing these concerns.

At times Luke discerned and expressed the losses he was aware were happening within him giving rise to his fears and grief. Sarah continued to need to talk about her loss of her hometown. Lydia still vacillated between knowing or sensing her husband had died, and asking staff to help her search for him since she had been with him. Luke, Sarah, and Lydia remained deeply attached relationally to those aspects of their lives they had lost physically. Their grief resurfaced in feelings of shame, regret, uncertainty and sadness when they again realised their losses. They each needed and were able to articulate their experience of grief and loss. In the safety of established relationship with someone who is attuned, compassionate and responsive, the person is supported in revealing their inner turmoil. As demonstrated in Chapters 6 and 7, Luke, Sarah and Lydia were each supported by staff and family relationships and activities that seemed to bring them love and care, peace and calm, and meaning and purpose in their daily lives. These relationships and activities provided the deeper connections they each needed to sustain them after going through another episode of their recurring grief. Deeper connections were important anchors for people in finding meaning, purpose and well-being in this phase of their lives as the following section considers.

8.3 Voice Making Deeper Connections

This theme identifies how over time people made deeper connections with those aspects of life that continued to be important to them. In seeking to understand the relevance of the person's voice to their spiritual dimension, I use the concept of spirituality as the person making connections to who and what are the important aspects of their life (see Chapter 2). This is a helpful segue and I use this approach in analysing the data. Their spirituality is the dimension by which each person transcends self to participate in the pattern of life as an intra-connected being, composed of body, emotions, mind and soul, and inter-connected with others, God and/or other significant aspects of their life (Hudson 2007; Miller-McLemore 1996). In this section I consider the ways the person seeks to express and/or enact their voice in connecting with their own self, or through the arts, or in hospitality and reciprocity, or with God/Higher Being and religious rituals. I demonstrate these aspects of the person making deeper connection through their voice in the following sub-themes, before I move on to the final section of Voice connecting with Life's Ultimate Meanings.

Voice: connecting with self

This sub-theme acknowledges that the person may consider maintaining ongoing connection to their identity very important to them. Voicing their own story was identified as an important way the person connected with and affirmed self within, and promoted their identity with others. This understanding is shown in the example of Paul below.

Paul

Paul is able to voice his continuing memory and awareness of significant aspects of himself and his identity, and also previously making appropriate decisions in his career, as shown in the next extract.

As Paul, his wife Bernice, and I conclude our conversation Carer Briony arrives with a gift for Paul:

> *Paul (noticing Briony arrive): Hello. How are you? Briony: I'm good! I brought you some magazines of ships, Paul. Paul (looking at them with a smile and a wide hand gesture): It's me! Briony: "The magnificent saga of man's quest of the seas." Bernice: Two of his sons went to sea, joined the Australian Navy, didn't they? (to Paul) You were on working ships…well he came ashore to be with his family.*

> *Because in the 60s he was away and his family was growing up…and it wasn't very good for them so he decided [we'd] come to Australia and give it a try…So he dropped his name and said if there's any positions coming up…and got a message not long after… Paul (laughing): I think it. Julie: It was a good decision…*
>
> *Extract 8.10 (AT, FRI, DRm, Paul and Wife, 2/07/2018).*

Paul greets Briony warmly and courteously as he knows her well. As part of the way she supports residents Briony continues to make practical gestures. This day she has thoughtfully brought some sea-faring magazines especially for Paul, knowing he appreciates them. As Paul receives this gift he connects it with his identity and story, exclaiming with delight, "It's me!" Bernice tells Paul's seafaring story and then his decision for the family to emigrate. Earlier Paul had told me this part of his story, regarding the significance of his family, but only in a brief sentence. I only understand its full meaning now in this episode with wife, Bernice's explanation. As he follows Bernice's explanation Paul again expresses his decision to get a position on-shore to care for his wife and family. Briony and other staff know Paul's story and continuing identity, and pay attention in practical ways to reinforcing this with him. Paul responds affirmatively with words, gestures, and facial expressions to this acknowledgement.

Voice: connecting through the arts

This sub-theme recognises that participation in activities of their choosing, such as crafts, music or artwork, created opportunities for some people to express or enact their identity and connect with themselves. These activities gave them opportunities to find and voice their meaning and purpose in their daily life (Meaningful Ageing Australia 2016), as shown by Thomas and Tim as exemplars.

Thomas

I regularly meet Thomas relaxing in his art place, humming or whistling. One morning Thomas explains why he puts tiny rolled-up paper neatly along his art table's edge:

> *Thomas: I put them along there like this. There'd be 50 odd there. Julie: Why do you put them there, [Thomas]? Thomas: that's a good question…Yeh, (laughs) That's a good question… Julie: They look lovely. Thomas: Yes (lifting his head proudly) … Julie: So how do you feel about your pictures? Thomas: I'm very proud, and I've taken them to the world. Everything I've got is for the world, and I don't allow anyone else to have them. They have a habit of taking all these (He firmly points and grimaces at the tiny papers)…Then they're not very happy because this is not very soft (he holds up his fist)…if they steal them because it's just not fair…They're put there by [Thomas]…This is what I've given to the world. Julie: It's important to you… Thomas: Very important. I can't help it. It is so beautiful and I feel (pausing and putting his hand on his heart)…good. When I came here, I was that tall (shows*

> *the length of his finger) I brought all of these to life and put them up there (as he looks at the wall decorated with his coloured pictures).*
>
> *Extract 8.11 (AT, RI, Home 1, Art Place, Thomas, 18/12/2017).*

Thomas voices his ownership of this place. He explains his activities with clarity and conviction. “They’re put there by [Thomas]…This is what I’ve given to the world”, highlighting their importance to him, bringing him pleasure and purpose as his contribution to others, even the world. Using dramatic words and facial expressions Thomas is able to respond to my interested questions. He enacts his voice in his artwork, decorating his art place with his art and giving pleasure to others as his gift to the world. Whenever staff compliment his art Thomas offers them a picture. He is able to clearly display his self-understanding of his becoming, using finger gestures to show how much he has grown since coming to the home. The lifestyle team’s innovative intervention enables him to enact his storied-life, identity and agency with pride. In being acknowledged and affirmed, his needs are met and this helps Thomas to maintain his self-esteem, well-being and calm.

Thomas’ story was, and continues to be, about contributing and making a difference wherever and whenever he can (POD, Book 1, 18/12/2017). Later I reflect on this encounter with Thomas:

> *I don’t readily understand all that Thomas tells me in his stories but I enjoy them, listening intently and gaining a sense of his emotional intent through his tone and body language. I sense that through his artwork Thomas has grown in his sense of self-worth. Through his artwork and giving this to others he is able to connect with his identity and with others giving deeper meaning, purpose and joy to his daily life.*
>
> *Extract 8.12 (RJ, Book 1, Thomas 18/12/2017).*

I observe that Thomas’ story is vitally important to him. He wants his storied-life to be heard and valued by others as he performs it avidly. Not all carers understand his artwork’s importance to him, as I reflected on in a later observation of an interaction between Thomas and a carer:

> *I have also observed that some carers seem to have a “take it or leave it” approach, listening or observing briefly but seeming not to take in what Thomas says. Rather than sitting and listening to him they relate to him functionally, for example directing him to his art place. Today I heard a carer ask Thomas why he places paper balls on the table. Thomas did not seem to hear her question and she did not notice this. When I ask the carer she repeats her question. Thomas replies, “I don’t know.” So different to the reason he gave me that perhaps he forgot or maybe did not want to share with this carer (see Extract 8.11).*
>
> *Extract 8.13 (RJ, Book 2, 5/02/18).*

Thomas notices when staff are attentive and listen to what is important to him, expressed in words and gestures regarding his art space and connection with his artwork. By and large the experience of living in the home has been affirming and transformational for him, and a significant means for Thomas to enact his voice.

Tim

Tim is a person who connects deeply with music and singing. In getting to know Tim I make field notes of our interactions, and his partner's and staff's comments:

> *Capability assistant Joylene regularly organises a "60s karaoke" show for Tim and others (POD, Book 2, Timothy, 19/07/2018, 27/07/2018). One afternoon a performer gives a concert, beginning with The Beatles "All My Loving." Immediately I look at Carer Mercy, saying, "Tim would love that…Is he awake to come?" Tim is immediately assisted to come. On hearing the song, Tim joins in with his low, perfectly pitched voice, "All my loving I will send to you"…(AT, RI, Home 2, ARm, Timothy, 4/07/2018).*
>
> *Extract 8.14 (POD, Book 2, Timothy, 8/08/2018).*

Engagement in creative activities that are meaningful to Tim gives him opportunities to reminisce with his senses and non-verbal gestures. Connecting through 1960s-70s music is meaningful to him, along with other activities with his partner and certain staff.

Music and artwork were significant forms of the arts through which many, like Thomas and Tim found meaning and purpose, pleasure, and well-being in their lives. Other people responded with their voices and facial expressions to songs that they knew by heart, heard on the CD player, or performed in the concerts, singalongs, and church services. Some people found participating in craft work stimulated them to reminisce about their storied-life. Each person who had previous connection with the arts might desire to continue this connection, and express and/or enact their voice through this medium.

Voice: connecting in hospitality and reciprocity

In this third aspect I explore how some people voiced their ongoing capability and capacity to offer hospitality and reciprocity to others in relationships. This approach to their daily life was often consistent with their storied-life. RSM Sue acknowledges that many people continue to make their unique contribution in this communal home. In the next extract Sue makes a bold statement about the impact of being in a community to the quality of the daily life of residents:

> *Sue: But I'm absolutely convinced a number of our residents have had longer lives through the quality of care, and being with others…People don't have to talk...It's just a presence around each other provides a degree of comfort…So, we have*

> *strangers that become amazing givers to each other...That people in the moment of their everyday lives have been happy…contributing in some way to their own community that they live in.*
>
> *Extract 8.15 (AT SI, Home 2, Office, RSM, 8/08/2018).*

This RSM identifies that many people desire, and are still able, to make their unique contribution to others as an expression or enactment of their voice. In being together, in companionship and interaction people are no longer strangers but become caring and interdependent with one another. Sue reflects that people's sense of well-being, contentment and comfort, and even living longer, are enhanced by living with others, being cared for and contributing to others in relationships in this home. Some spontaneously and graciously give to others, as exemplified by Lydia in the following extract.

Lydia

Lydia and I are sitting together in the loungeroom. A carer has given me our morning tea and Lydia asks me:

> *Lydia: Have you got anything to eat? Julie: Yes, here in my hand, Lydia… Lydia: And you? Julie: Yeh, would you like some? Lydia: Shall we cut it in half? Julie: No, no you have it all… Lydia: All? (rising inflection in voice)…(Lydia is still pulling at the paper serviette, not focusing on eating) Julie: No…you want that napkin to be shared. Do you want me to cut it in half… Lydia: yes. Julie: OK, I'll share it with you... Lydia: Thank you… Julie: That's very thoughtful of you… Lydia: You have some (Lydia is still focusing on tearing and sharing the napkin). Is this for the dip? (wiping herself with napkin)…And now I've got it. Julie: You've got it, yes. Thank you for sharing it with me...I love your smile. Lydia (smiling): Yes, I'm not silsy (sic-silly?) (sighs)…I haven't got any…I've got. Julie…It's always very important to you that you share what you have? Lydia (definitely and quietly): Yes. Julie: That's lovely. Lydia: You've got one? Julie: Yes, I've got one. Thankyou.*
>
> *Extract 8.16 (AT, RI, Home 1, DRm, Lydia, 1/12/2017).*

During this time together it seems food is most important to Lydia. Is this because I have arrived and she wants to offer me hospitality in the sharing of food, and/or is she hungry? Lydia is intent on making sure I have some food with her question to me and trying to tear apart her napkin. In the past she would have performed this cultural courtesy with the loaf, in providing her hospitality of home and food to others. She asks, "Is this for the dip?" as cultural food to share. At one stage I take over, presuming to break and give out the bread and give it "all" to Lydia. When I realise my discourtesy, I pull back and receive from Lydia who appears determined to tear the bread and share, and not have it “all”. Lydia expresses her hospitality, as she demonstrates her capability and capacity to perform an extended and significant embodied ritual with me. It seems this occasion becomes spiritually significant for us, similar to Lydia hosting a meal for her guests. Lydia has deeply appreciated this cultural ritual through her life, according to her son (AT, RFI, Home 1, LRm, Lydia and Son, 22/01/2018). While Lydia continues to speak she performs her ritual with her hand movements and her attentiveness towards me. As I thank Lydia, she affirms herself to me with “Not silsy” (sic), with a smile of pleasure and a sigh, having hosted me (POD, Book 1, 1/12/2017; RJ, Book I; OG-Lydia).

Subsequently, during the interview with Lydia and her son, Theo explains aspects of Lydia’s story:

> *Theo: Mum has always been kind and helpful to people. Mum and Dad provided leadership, hospitality and refuge in their home for families, relatives and friends newly arrived in Australia, sharing their knowledge generously with my adopted “aunties” and “uncles” (Lydia nodded her agreement as Theo talked).*
>
> *Extract 8.17 (AT, RFI, Home 1, LRm, Lydia and Son, 22/01/2018).*

Theo speaks of his parents’ prominent lives, both in their homeland and in their Australian ethnic community. The sharing of these stories is deeply embedded as Lydia’s storied-life with her family, their ethnic community and cultural heritage. Lydia continues to embody and enact these rituals and cultural courtesies of hospitality, spontaneously and graciously.

The next extract articulates how people continue to care for one another, as described by John’s wife, Frances, who volunteers on several days in the house where John lives:

> *Frances: Sometimes I watch people. And some do pick up on somebody needs help…and they don't mind giving time to others. I guess they still remember something…their caring natures, the way they are as people. I think that even though they're like that, their mind's still…*
>
> *Extract 8.18 (AT, FI, Home 2, Café, John’s Wife, 16/07/2018).*

Frances has observed that some people are aware of others and especially realise when another person needs support. In response the person desires and is able to spend time with the other person, showing their care. The person’s embodied awareness, agency and personality traits remain and become apparent in their caring enactments towards others.

Several staff members confirm that relationships are reciprocal in the giving and receiving of care with the person. The next two extracts with Capability Coordinator Serina and Carer Roy, depict the person noticing and caring for these staff members in their time of need:

> *Serina: One day I knew I had bad news…my granddad…had died and they'd let me know here. I thought, oh I'm fine…So, I went into the house…and the first thing she said to me is, "You need a hug." "Oh my God, thank you"...That was magical for me. She gave me this almightiest hug, and then she let me go…but she knew.*
>
> *Extract 8.19 (AT, SI, Home 2, Capability Coordinator, 8/08/2018).*
>
> *Roy: Yeah, I try to find time…That's all they need… little moments… The other night we had a hell night…Then Felicity was kicking off…We just had a moment, she went "I love you". Put her hands out, gave me a hug…Yeah, it just made my night.*
>
> *Extract 8.20 (AT, SI, Home 2, DRm, Carer, 7/08/2018).*

Both Serina and Roy recognise that people have expressed and enacted empathy and compassion to them on occasion. Without needing an explanation, each person has become aware of their upset at that time. In words and gestures, they have responded by providing care to Serina and Roy, with whom they have a relationship. Nurse Martha sums up how these times unfold in interactions:

> *Martha: But it's just good to have that feel of conversation with them whether they're understanding it or if they're not…*
>
> *Extract 8.21 (AT, PC, Home 2, Nurse, 21/08/2018).*

In the sharing of reciprocal care and relationships there is a "feel of conversation", as a deeper level of communicating. The person demonstrates responses of supportive and affirmative actions, words, sounds and embodied gestures towards staff, who also affirm them and lift one another's spirits. Such reciprocity affirms the person not only as a care recipient but as a care giver, with continuing capabilities and capacities to also care for the carers, who likewise are vulnerable and need support at times.

Voice: connecting with God/Higher Being and religious rituals

In this fourth sub-theme I explore how several people expressed their identity and storied-life, and found meaning in connecting with God through faith rituals. Some people expressed their agency in choosing whether they would attend the church service when asked by staff on the day, as in the following example of Hannah, who is with Cleaner Clare when I invite her to the church service.

Hannah

> *Julie: Hello, Hannah. Hannah: Yes, mmm. Julie: Hannah, it's music and church - would you like to come? Hannah: Music and… Julie: With Chaplain, would you like to come? Hannah: Who's Chaplain? Julie: Oh with the Church person, would you like to come? Hannah: Oh! Yeh…Can [teddy] come? Julie: He certainly can!*

> *Hannah: He's a bit wet still. Clare: He needs a bath really. He's just had a face wash…Miaow… Hannah: Miaow. Julie: I can see you two are good friends. Clare: I'll hold teddy while you stand up… Hannah: He's nice, isn't he? Clare: Sure is… Let's put him there… Hannah: Thank you! Clare: You're welcome.*
>
> *Extract 8.22 (AT, RI, Home 2, ORm, Hannah, 4/07/2018).*

Hannah responds positively when I clarify I am inviting her to church. Clare knows Hannah's weekly activities and facilitates her attendance at church, always washing teddy in readiness. Being together often, Hannah and Clare share a convivial relationship obvious in their fun cat language known only to them. Hannah responds to Clare enthusiastically, both verbally and in her gestures.

When we arrive in the activity room I notice that the chairs are placed in a semi-circle with the "altar" table located centrally at the front and close to the chairs, giving me the impression of an intimate and inclusive place wherein each person has a front row seat. I later describe my observations of the church service in the following field notes:

> *Chaplain Sharon welcomes each person as they arrive. Hannah greets her and holds her teddy up to Sharon to bless. Each person seems engaged throughout the varied program. During the showing of photos and Sharon's commentary, she goes around inviting and engaging responses from each person, such as eye contact, a sound, a nod, a word or phrase, or a memory, and Hannah makes her comment. At the conclusion of the service Sharon moves around the group farewelling each person, and Hannah responds warmly.*
>
> *Extract 8.23 (POD, Book 2, Home 2, GA- Church Service, 4/07/2018).*

The church service is one of the popular weekly activities, with people choosing to come when invited. Chaplain Sharon's presence is warm, welcoming, and inclusive of each person. She has specifically created her presentation and the simple format for the group. Using familiar old hymns and short prayers in a provided folder, a short Bible reading, and an interactive chatting format for her brief talk with large calendar photographs on a particular theme, this Chaplain engages everyone. People often find the hymn number, or are assisted by the Volunteer. They participate in following the words, singing and praying together. They gesture their appreciation and attentiveness in their facial expressions. Sharon goes around the group inviting the comments or gestures of each person. At the end of the service Sharon gives a blessing and then goes around the circle, personally saying farewell to each person before staff assist them back to their house.

Hannah later tells me that she used to go to the Church and states her ongoing connection, "I may not go but I'm still there" (AT, RI, Home 2, ORm, Hannah, 19/07/2018). Specific religious rituals help people who attend to have connection with God or another Higher Being. Through rituals the person expresses and enacts their faith in tangible and meaningful ways, and is encouraged in their sharing with others. For example, in remembering and saying the Lord's Prayer, the "Our Father" people confidently and communally participate together.

Chaplain Pat defines his understanding of the person's voice in one-to-one and group spiritual care:

> *Pat: I think their voice is in two ways… about their being present personally to me … in a broader sense to the community even in coming to the church service...and about their response…Often the music elicits not always a verbal, but a response and that is their voice in this community…the gift they give, they share what is happening for them…and hopefully our gift of presence and response to them, individually and communally…and that is different for everyone.*
>
> *Extract 8.24 (AT, SI No. 3, Home 1, Office, Chaplain, 12/02/2017).*

Pat considers the person's very presence in choosing to participate enacts their voice of agency and contribution. Each person expresses their inner experiences differently, often non-verbally or by joining in the singing and prayers. In a spiritually connected way this is "the gift they give", their responsive contribution reciprocating another's care and enriching the interdependency of community. For those participating, spiritual rituals affirm the person's worth and provide a communal place for them to express their voice.

8.4 Voice connecting with Others in Life's Ultimate Meanings

The participation of each person in the research gave them the opportunity to testify as to how they lived and experienced this final phase of their life. People's affirmative and appreciative words and gestures within interactions and relationships, appeared indicative of the value and meaning they gave to these experiences in their daily lives. These events seemed to connect with a deeper part of themselves, their agency, identity, storied-life and spirit as expressed and enacted by John, Naomi, Philip and Sarah in the following extracts.

John - raising a hum

John's storied-life shows that his identity has been about caring for others, and this continues in the way he offers support to others in the house. He builds relationships, especially with his friend, Felicity. John's wife, Frances describes their connection:

> *Frances: When John came for some reason him (sic) and Felicity just clicked. They'd walk around together, and chat. Even when they're not talking too good they still chat together, and they laugh. You think what the heck are you laughing about? Yeah but…*

> *Extract 8.25 (AT, FI, Home 2, Café, John's Wife, 16/07/2018).*

John and Felicity have been able to foster their friendship and continuing connection through their mutual appreciation, chatting and laughing together in their sounds, single words and non-verbal language. Their choice to be together indicates that their companionship is very important to both of them. One morning John and Felicity do a circuit pushing their walkers around in procession, silently spurring each other on. Their relationship appears to encourage John to initiate interactions with others, as seen in the following example:

> *John stops in front of me humming. I get a tissue, wiping a drip off the end of his nose. I pat his back for a short while. As I pat his back John's voice in his hum becomes stronger as he stands still. Julie: How are you today?... Have you had a busy day so far? Are you going to move off again, John?...OK…It's nice seeing you again. See you later on.*
>
> *Extract 8.26 (POD, Book 2, John, 19/07/2018).*

John's humming indicates "I am content". He has come to see me as familiar, even a friend, and his hum and my pat deeply connect us. Then John moves on after Felicity. I have observed that patting other's backs is John's loving touch with his wife and others. Such brief exchanges are meaningful moments expressing and enacting mutual appreciation, arising out of being together, sitting, interacting, listening and responding within an atmosphere of relaxed friendship.

Naomi - "I still…Why we in the worl"

Like John, Naomi shows by her behaviour that she values being with others and sharing in deeper conversation about life's meaning and purpose. This is demonstrated by her insightful comments in the next extract.

When Naomi, husband Beau, and I sit together again, Naomi is able to testify to the value of shared time together:

> *Naomi (delighted tone): This is lovely! Me, me. Julie: Oh, thank you, Naomi. It is about you, you…when we spend time together… Naomi (following my words): Yes. Beau: When you can work out what it's all about let me know will you? Julie: Well I think you both summed it up...when we spend time together…that's really special. Beau: Yeah. Naomi: Yes. Julie: You know that, don't you? Naomi (definitely): Oh yes. We, we, we, we, we. Julie: We, you see, we. It's about we... Beau: I see, is that what it means? Naomi (definitely): of courses. Julie: Maybe just one or two words... Naomi: Yes, it is. Julie: Me and me and we… Beau: Yes, we. Julie: Being together. (Beau then tells a long story about their family.) Naomi (eventually interjecting): Oh man, oh. Julie: Yeah, it's good life isn't it? Naomi: Yes, yes, yes…*

> *Julie: So I listen for Naomi's tone, and try and match it… Beau: Oh yeah. Julie: Just quiet and gentle. Naomi: My, my, my place… (Beau continues to tell their story about living locally.) Beau: Naomi used to love swimming. Naomi (with a big sigh): Yes. Beau: I used to help her out of the water because her legs were raw. Julie: But you love the water? Naomi: Yes. Julie: Wow. Naomi (sigh): Oh yes. All I wonder. God! I still, I still, I still, I still. Julie: You still wonder? Naomi: Yes, ooooooh…*
>
> *Extract 8.27 (AT, RFI, Home 2, DRm, Naomi and Husband, 6/07/2018).*

Naomi demonstrates her appreciation of this shared occasion, speaking briefly and profoundly about the significance she gives to it with, "This is lovely! Me, me". Beau expresses his desire to understand what Naomi says. Naomi shows her ability to follow Beau's words. She engages in the conversation aptly with words and gestures, echoing many of Beau's words. She extends the meaning of the conversation in the value of us being together, "We, we, we…". Naomi aptly responds to Beau's growing understanding with "Of courses!" Then Naomi proclaims strongly with her embodied enthusiasm and understanding, "All I wonder. God! I still." Perhaps she means, "I still enjoy swimming like I always have..." Or perhaps "I still remember, I still feel…" Perhaps also metaphorically, "I still am alive, I still am here. I still enjoy, I still have something to contribute…" In her lived experience Naomi sometimes struggles with aloneness and sadness. Yet she still expresses the wonder of her life when interacting with her husband and others in relationships.

Sometime later I meet Naomi and Beau sitting in the home's Café with friends, Jack and Mavis, who are visiting. Naomi appears unsettled, perhaps because these people or this place are not familiar. She turns towards me, reaching out her hand. Beau introduces me and my study, as including Naomi. After I affirm Naomi's involvement looking at Naomi. Jack and Mavis respond:

> *Jack: So, there you are, Naomi, you're in the spotlight… Naomi: Yes… Julie (I nod to Naomi): It's very important, isn't it? Naomi (looking at Jack): He is…you're love. You're love (definitely). Jack (sounding emotional): Thank you! (Immediately turning to Beau they discuss issues about dementia, while Naomi is speaking)*
>
> *Naomi: Well? That's wha we in this worl, worl, worl…why we're in this worl, worl, worl…..*
>
> *Extract 8.28 (AT, RFI, Home 2, Café, Naomi, Husband and friends, 16/07/2018).*

Naomi, looking at the friend, immediately responds to his affirmation, "You're love…" Seeming to be affected by her affirmation he replies, "Thankyou". The dynamic of what then transpires quickly is difficult to capture in script form. With profound and definite words Naomi voices the reason she believes people are in the world. However, Beau and the two friends engage in conversation with each other, and do not appear to hear the profound comment that Naomi makes.

Just then Carer Carol comes by and seeing Naomi, stops to greet her and chat with her:

> *Carer Carol (passing stops to talk with Naomi): Hello, Naomi! Naomi (enthusiastically): Yes! Carol: How are you? Naomi:…Very good. Carol (hugging each other): Nice to see you. You been good? Naomi: Very good…(Carol leaves).*
>
> *Extract 8.29 (AT, RFI, Home 2, Café, Naomi, Husband and friends, 16/07/2018).*

The conversation between Naomi and Carer Carol is an enactment of Naomi's life-affirming words regarding the meaning of loving relationships, of being in the world with others, and of contributing as Naomi's reason for being. Philip also demonstrates his awareness of his vitality with his exuberant words when we walk together one day.

Philip - "I feel I'm alive"

I realise how important our times together are to Philip when he freely voices his feelings:

> *Philip: These are nice big walls, aren't they?... Julie: We've gone full circle. Philip: Yes, you can see what you're doing (exuberantly). Oh, God! Julie (concerned): Are you alright, Philip? Philip (affirmingly): I feel I'm alive. (Philip raises his hands and wriggles his fingers)… Julie: Everyone you meet, Philip, you smile at. Philip: Yeh well I like a say hello. And you can speak a smile. Easy. Julie: That's a nice thing to do, isn't it?… Philip: Just for them.*
>
> *Extract 8.30 (AT, RI, Home 1, Passageway, Philip, 19/01/2018).*

With his gestures of hands raised high in the air and his enthusiastic words, Philip demonstrates the meaning of our being together. He feels he is alive and expresses and enacts his joy. I have repeatedly observed Philip remaining true to his courteous and caring identity, inclusive of everyone he meets. He enacts his capabilities in his repertoire of courtesies, greetings, farewells and affirmations of others. Philip is glad to be alive with others in meaningful relationships, interaction and shared activities. This time together seems an uplifting spiritual experience for us both (RJ, Book 1, 19/2/2018; PN-Philip).

Sarah - "Good to say it"

Having met several times, during our usual farewell ritual Sarah affirms our time spent together:

> *Sarah: You haven't been around. But you've been around a fair bit. I've found that. Julie: Thank you, Sarah. Sarah: That's alright. I'm glad. I've got a feeling about it too myself. Julie: You have got a feeling about it. Sarah: I've got a little bit of your feelings there. Julie: Thank you. Sarah: That's alright. Good to say it. Julie: Good sitting with you. Sarah: OK, darling, righteo. I hope we didn't, you know. Julie: No,*

perfect. I was really glad. Sarah: Oooh, OK (chuckles). Julie: Very special thank you. Sarah: OK Thank you.

Extract 8.31 (AT, RI, Home 2, Servery, Sarah, 5/07/2018).

Sarah affirms our connection through our deepening relationship over time. She declares her feeling of our relationship and conversation as being enriching to both of us. She confirms the importance of stating this and the worth of voicing gratitude in the moment to acknowledge and affirm one another. Sarah also intimates an apology if our togetherness has not somehow been right. I promptly affirm to Sarah how much I value our being together and thank her. Our spirits are somehow warmed as we sense and acknowledge our deeper connection.

When I return to the aged care home later Sarah is no longer moving around in her wheelchair. She is now sitting in a comfort chair in the lounge room of her house with others. Carer Deidre puts her face very close to Sarah's, and they look into each other's eyes. Sarah holds her face between her hands and says with her characteristic smile, "I love you" (AT, GI, Home 2, LRm, Sarah, 5/02/2019). Sarah's statement is a deeply moving expression and enactment of her testimony to her life, and the very deeply connected relationship she shares with Deidre.

Each person voiced their spontaneous responses in the moment, expressing their thoughts and feelings concerning their awareness and appreciation in being alive. These statements showed their enjoyment of their lived experience, promoted in relationships with others and in being together, interacting and participating. Moreover, in spending time together in interactions and as relationships deepened, I experienced people using their verbal language in their words singly, in phrases, and in sentences. Despite their language abilities being affected by dementia, many expressed their responsiveness and the meaning they gave to our interaction and relationship.

Each of the people featured in this study chose to participate in relationship with me and voiced their participation in their own way, according to their voice repertoire. None of the twelve participants for whom I had received full consent as central participants died during the study. Several died soon after completion of the fieldwork, and eight people had died within the year following the field work. I did not include people who were receiving palliative care services as discussed previously. Thus, the research was an opportunity for each person to voice their words and gestures as an expression of their life's meanings. This expression might be considered a latter testament to those aspects which they believed to be significant to their life. The person's storied-life continued on into the present times we shared. Each person was able to testify in this last phase of their life to what was essential and ultimately meaningful to them as an aspect of their last will and testament. Thus their voice in words and /or actions had particular significance.

8.5 Summary

In this chapter I have shown how, in experiencing deepening relationship, each person continued to express and enact their voice, many with deepening content. Being with, listening to, observing and participating in relationship with each person over an extended period created a sacred space of trust and openness between us. This space gave each person an opportunity to voice themselves at a deeper level. At times the person indicated that their sense and memory of former experiences became vivid in their present. Sometimes the person expressed in their words and/or non-verbal language their unmet needs, unresolved grief, and at times their unresolved regrets and shame in not understanding why they could not return to how their life and relationships had been previously. On some occasions in narrating their story, past feelings and thoughts surfaced as grief responses to the many forms of loss in their life continuing into the present.

This chapter has also demonstrated that as the relationship between the person and others grew and deepened, the person might express their valuing of their personhood in displaying enthusiasm, appreciation and/or enlivenment. When given the opportunity, it is noteworthy that several people expressed themselves verbally when others considered them no longer capable of doing so. These people also were able to express a pithy comment in single words, a phrase or a sentence, indicating the meaning and significance they attributed to the particular occasion and their lived experience. There were several examples of people offering me hospitality and engaging with other residents and staff in reciprocal relationships, in which they also provided care. At these times the person became visibly elevated in mood and was transformed, becoming in the moment, evidenced in John’s humming and Lydia’s smile and comment with definite tone, “I’m not silsy”. The expression of their voice connected them with others, nurturing their spiritual dimension and sense of belonging, participation and well-being, in interdependent community.

This chapter has also shown that the person continued to voice their spirituality as they formed connections with who and what was important to them. These aspects of their life gave them a sense of meaning, purpose, life and love. Some people were able to articulate this as enacting “Me”, giving them a sense of their ongoing identity, meaning and purpose in their daily life. Connections might occur for the person within themself in their sense of self-worth, connecting with artistic pursuits, connecting through enacting hospitality and reciprocity, connecting with God, religious rituals and/or transcendence, and connecting with others and their source of life. In being thus present and connected in ways significant to them, each person testified to their unique value, place and participation in the world. In enacting their voice, the person was meeting an ongoing human need to be in meaningful relationship with others.

Many staff recognised that being with people with advanced dementia is necessarily respectful, interactional and relational. Thereby these relationships became personally meaningful for them also. Several staff stated acknowledgement, understanding and affirmation of the person and their voice are imperative in excellent care praxis. In their interviews, staff gave their perceptions regarding the significance to the person in having their voice. Most staff in this voluntary sample responded positively, taking the position that having their voice remains a vital and central aspect of the daily life of the person with advanced dementia. The intentional provision of a positive interactional and relational environment is conducive to encouraging the person's voice and their daily quality of life and well-being. Thus, friendly reciprocal interactions continued as a dynamic flow, generating further connection and deepened relationships with each other.

The analytic narrative over Chapters 6 to 8 has described the lived experience of people with advanced dementia in an interactionally and relationally rich setting. In this environment they have expressed or enacted their voice with strength, ability and capacity while experiencing challenges, changes and limitations in aspects of their lives. There is a sense of the person *becoming* in many encounters: becoming engaged; becoming stimulated to take initiative; becoming connected; and becoming expressive of appreciating shared time together.

My approach to analysis has endeavoured to privilege the voices of people with advanced dementia to understand their lived experiences, what they value, and what is significant to them. In the next chapter (Chapter 9) I consider the findings that resonate with previous research and the new discoveries that I have identified. The chapter also explores the policy and praxis implications arising from the findings and proposes what might constitute transformed praxis to promote the voice of the person.

CHAPTER 9 DISCUSSION ON THE LEARNINGS

Introduction

In this chapter I discuss the overall findings within the context of the themes presented in Chapters 6 to 8 to answer my research questions, which again are:

What are the ways the older person with advanced dementia expresses or enacts their voice?

What enables the voices of older people with advanced dementia in residential aged care?

Chapters 6 to 8 have presented how people with advanced dementia expressed and enacted their voices demonstrating their continuing consciousness, awareness and expressions of self, and their responsiveness to others and their environment. These chapters also showed how the person initiates their own voice and is encouraged by other residents, family, and staff members. In this chapter I reflect on the ways this study has resonated with or extended previous studies, including very recent studies, or provided new knowledge. I also elaborate on the praxis implications, again explicating an ethics of care underlying this praxis for promoting the voice of the person with advanced dementia within residential aged care.

Chapter 9 discusses the findings in the following sections: 9.1 ‘Each Person has their Voice’; 9.2 ‘Interactive Activities Connecting Voices’; 9.3 ‘Inclusion of Voices in Relationships’; 9.4 ‘Voice Enacting Agency, Identity and Storied-Life’; 9.5 ‘Nurturing the Person’s Spirituality through their Voice’; and 9.6 ‘Relating the Findings to Policy and Praxis Development’. I also elaborate on the praxis implications for promoting the voice of the person with advanced dementia within residential aged care. In the conclusion I draw the thesis findings together, and in so doing provide a revised definition of the voice of the person with advanced dementia.

9.1 Each Person has their Voice

This study has not been a homogenous portrayal of the daily lives of people with advanced dementia. Rather this narration represents the diversity of people and their lived experience, enacted in their voices. Furthermore, their voices express their responsiveness to who and what has prompted and/or facilitated their participation through their day. This study has found that each person continues to express or enact their voice with their capabilities, capacities and dexterity. These findings concur with other recent studies (Clare, A et al. 2020, p. 140; Vigliotti, Chinchilli & George 2019; Watson 2019) that have found many people with advanced dementia retain the desire to engage in interactions and relationships with other residents, family and staff members. This study resonates with previous studies by Watson (2019) and Mok and Muller (2014) that not only does the person express their desire, but they also display the extent to which they continue to take initiative with intention, and demonstrate their retained abilities. Firstly, this study has found that the person facilitates their own voice by calling out to gain another's attention, to achieve their particular purpose at the time. The person's expressions of initiative indicate the person's retained capability, intentionality and dexterity in using verbal or non-verbal prompts to enlist the assistance of others. Through their attempts to gain a staff member's attention, the person also realises their need to change their situation positively. Secondly, this study has demonstrated that the person facilitates their own voice. They do this by calling out with words or gestures of welcome, such as smiling and reaching out their hand, primarily to gain another's attention, and to socially connect and engage with them. From a strengths-based perspective the person enacts their ongoing desire, social ability and agency in choosing to join others and participate in interactions and relationships at various times through their day. The person is often able to recognise another person, staff or family member who is familiar, and may initiate reconnecting and interacting with them as Quinn et al. (2014) have identified previously.

This study further validates earlier research which has found that the person's responsiveness is premised on their retention of awareness (Clare, L et al. 2013). The person with advanced dementia continues to display awareness in reacting to their internal embodied stimuli, such as changes due to pleasure or pain and discomfort as a pre-reflexive response (Godwin & Poland 2015; Kontos, P 2012). They also notice and respond to external stimuli such as the sounds and movement of others in their proximity or at a distance (Quinn et al. 2014).

My findings align with earlier studies identifying that the person with advanced dementia expresses and/or enacts their voice in particular ways:

- The person communicates in their own "communication repertoire", "a unique communication repertoire comprising a variety of nonverbal components, spanning eye gaze, emotion expression, and movement" (Ellis & Astell 2017, p. 1).

- The person uniquely enacts their self, according to their ongoing personal characteristics related to their identity (Godwin & Poland 2015; Perkins et al. 2015), agency (Boyle 2014; Cahill & Diaz-Ponce 2011), and storied-life in interactions and relationships (Kontos, P et al. 2017) (see Section 9.4).

This study has offered the following significant new insight and contributes further to the current body of knowledge. The research has found that rather than functioning separately, the person expresses and/or enacts these various features of their voice in the one encounter and often simultaneously. I have termed this intertwining functioning of the person's voice their "voice repertoire" which is unique to them. Their voice repertoire signifies that the person is accomplishing or effecting their voice according to their particular capabilities and capacities. The person uses their “communication repertoire”, being predominantly non-verbal or verbal language or a blend of both, accompanied by their personal characteristics, their agency, identity and storied-life, so that these features function in partnership.

A further new and significant contribution of this study is the finding that many people retain an intact capability, capacity and dexterity to express themselves verbally. In extending the previous research of Ellis and Astell (2017), I have found that the person with advanced dementia may use verbal language of words singly, in a phrase, in sentences, and in extended comments. Depending on their voice repertoire, the person may use verbal components accompanied by appropriate non-verbal gestures and facial expressions. I have found that some people may engage immediately in conversation when they see someone approaching. Conversely, a person may appear to observe others nearby and eventually make a verbal comment in response. While I have been aware as a chaplain of people with advanced dementia maintaining their abilities with verbal language, I had not countenanced that it would be so generally apparent in them. As evidenced in this study the person may be prompted to express themselves verbally by the presence of another, especially an attentive listener who becomes familiar and develops relationship with them over time.

This study also has ascertained that many people display the capacity to maintain ongoing inter-action both verbally and non-verbally, over a length of time, from fifteen to forty-five minutes. This original finding again contributes to the current body of knowledge. The presumption anecdotally, and also by health care providers and ethics committees, is that a person with advanced dementia has very limited capacity and will tire quickly and lose interest or concentration (Gerritsen, Oyebode & Gove 2018; Gove et al. 2017). However, in this study this perception has not been evidenced in the majority of interactions with central participants from the initial sample, and those chosen as exemplars during analysis. This study has discerned that the person may maintain engagement displaying effort, energy and even enthusiasm for an extended period. The person’s capacity is usually dependent on the other person remaining interested and engaged with them. On occasion in this study, people have demonstrated their taking initiative to prolong the time together with me, displaying their awareness of my signals of bringing the encounter to a conclusion. They then seek to prolong our interaction with their reflective statement that they had more to say or wanted to stay with me, by maintaining eye contact, and/or their non-verbal gesture, such as reaching out and holding my hand.

This study has evidenced how the person may show dexterity in expressing their verbal repertoire to express their opinions, choices and responses to their family, staff or myself. In doing so they may use phrases or their intact and familiar social conventions, including formulaic sayings and courtesies. At times in response to my or another’s question or affirmative response, the person is able to state a whole sentence, comprehendible in both its syntax form and its apt content with particular recognisable words. In the same episode the person may also be able to display aspects of their identity and storied-life in their social conventions, courtesies and proverbial sayings. While researchers have previously identified social conventions, courtesies and proverbial sayings as interactive strategies the person with dementia uses, this study extends this finding to include people with advanced dementia (Davis & MacLagan 2014; Muller & Mok 2014). This study has also demonstrated how these interactive strategies are linked to the person's continuing expression and enactment of their personal characteristics, their identity and storied-life. This finding concurs with the research of Batra et al. (2016) who focused on the person's preserved identity and that the person continues to self-reference, express their preferences, and reference their day spent with others. Social courtesies and conventions such as formulaic sayings also seem to be retained by the person with advanced dementia as "unitary chunks" (Davis & MacLagan 2014, p. 98). These sayings are easily retrieved from their memory and often have shared meaning by the other that keeps the interaction flowing. Having observed the person's expressions of social courtesy, I have extended the findings of Davis and MacLagan. I provide the insight from this study that the person with *advanced dementia* may show ability to employ these long-practised customs to instil a sense of their respect, courtesy and appreciation into an encounter. Furthermore, I propose that using these conventions enables the person to manage their many and diverse encounters with others through the day in their communal environment. Bakhtin (1987, p. 69) identified similarly that the social conventions of utterance become habitual and useful in interchange, providing place markers that each participant in the dialogue recognises and assists them to know when to respond. In this study I have also observed that in an encounter the person with advanced dementia retains the ability to recognise the communication partner's familiar signs such as rituals of greeting and farewell. These signs, learnt and rehearsed over one's lifetime, have become embodied words and gestures, like a script that the person is also often able to perform repeatedly when they are in interactive situations.

Praxis implications

When a staff member uses the signs of interaction, such as greetings, courtesies and farewells, they set up the familiar scenario for the person that this situation is an interactive encounter. These rituals facilitate the person to engage in interaction, and at its end move on and not be left suddenly "up in the air" without company. The person's embodied interactive performance may further prompt the staff member's responses which gradually form affiliation and even kinship between them (Heshusius 1994; Muller & Mok 2014). Through an ethics of care displaying recognition, respect, responsiveness, and relationship staff affirm personhood as their intentional and integrated approach to care of the person. Lest the person forgets or is forgotten, "their personhood needs to be continually replenished, [and] their selfhood continually evoked and reassured" (Kitwood & Bredin 1992, p. 285). Staff replenish the person's being by attentively and affirmatively listening to, observing, and mirroring their sounds, words and gestures. Confirming the findings of previous studies (Eggers, Ekman & Norberg 2013; Ericsson, Kjellstrom & Hellstrom

2011; Walmsley & McCormack 2017), the words and actions of staff encourage the person’s ability to relate as they experience their worth, acceptance, and belonging. Positive acknowledgement by staff seems to maintain the ease of interactions and sense of cheerfulness between the person and others. When the demeanour of staff members, displayed in their facial expression, body language, posture, tone of voice and verbal language, is friendly and calm towards them the person may mirror this also. Adapting to the person includes giving them time, not interrupting, diminishing, nor outpacing them (Perkins et al. 2015; Walmsley & McCormack 2017; Williams, K 2011). Using querying inflections and repeating the person’s words and gestures affirms to them the other is listening and desires to engage. This pattern encourages more interaction from the person. According to their voice repertoire the person may then continue to comment or use non-verbal gestures to respond appreciatively.

The knowledge that the person’s voice repertoire has two major facets, both their communication abilities and their personal characteristics, is important for the staff member. This informs the listening and observing of staff to be attuned to each person’s unique voice repertoire. However, the current study found that while several staff articulated their desire to listen and empathise with each person, many staff were unable to identify the voice repertoire of specific people, and particularly their non-verbal language. This latter finding concurs with that of Cameron et al. (2020, pp. 1364-5) who found that staff rely on the person’s non-verbal gestures and behaviour to provide care. Yet, often staff do not know or relate the person’s non-verbal gestures and behaviour to their storied-life, and therefore are less able to interpret these signals appropriately. Accurate assessment and appropriate responses are challenging when the person cannot specifically define their needs. I would argue that appropriate care can be compromised when staff do not recognise and understand the person’s unique voice repertoire, enacting ill or well-being, pleasure or pain.

In summary, this study has identified that opportunities for positive interaction, one-to-one and in group activities, encourage the person’s experience of personhood. Interactive activities prompt the person to enact their voice and connect with others, as discussed in the next section.

9.2 Interactive Activities Connecting Voices

Group activities provide people with opportunity to express and enact themself in interactions with others, experience well-being and “to feel they matter as a person” (Watson 2019, p. 548). Recent studies have shown that their participation in these regular activities and specific programmes gives each person the opportunity to communicate with others, further motivating and strengthening their capabilities and capacities (Canning, Gaetz & Blakeborough 2020; Vigliotti, Chinchilli & George 2019). Many people in this current study showed that they continued to place importance on spending time with others and engaging in interactions and relationships. These findings also resonate with those of Cahill and Ponce (2011) that diverse interactive activities, one-to-one and in groups, accentuate the quality of life of people in residential aged care, providing social engagement and a sense of connection and belonging. Such participation also has positive health outcomes and is found to lift the person's mood (Beerens et al. 2018). Involvement in activities may also give residents a sense of pleasure, meaning, purpose and contentment and enable them to feel 'at-home' (Simpson 2006).

Praxis implications

Knowledge regarding the efficacy of interaction reinforces the value and role of staff such as chaplains, pastoral carers, lifestyle assistants, and volunteers who sit listening to and interacting with people. However, interaction is a necessity and responsibility of every staff member as an aspect of their caring attitude and ethical positioning towards each person, as shown in this study. Staff may facilitate the person's voice during the daily praxis of their various responsibilities. The person often shows their desire for more than a brief interaction that is only task-focused. Resonating with the findings of Hartmann et al. (2018), I observed and heard from staff that there are occasions through a person's day or evening when the person might appreciate interaction. These times are when people are assisted with their meal and afterwards, having morning or afternoon tea, or participating in personal care. Staff need to make the most of these opportunities with people. A review of recent studies commissioned by Alzheimer's Disease International concluded that the lack of physical and social activity are a major concern in many residential aged care settings, since "the majority of residents spend most of their time sedentary and inactively sitting or lying alone" (Fleming, Zeisel & Bennett 2020, p. 52). Both social isolation and loneliness are, according to UK statistics (Australian statistics unavailable), 22-42% more prevalent in resident populations compared with 10% prevalence in the wider community (Victor 2012). Those who experience social isolation and loneliness are at greater risk of negative health outcomes and poorer quality of life (Curelaru et al. 2021). However, Oyebode and Parveen's (2019) literature review into studies of psycho-social interventions found brief interactions between people and staff remain predominant, with an emphasis on correcting and controlling behaviours. It is vital that staff engage with people in a variety of ways more often and for longer to encourage their well-being (Oyebode & Parveen 2019).

During periods of Covid-19 lockdown and social distancing, the literature review of Curelaru et al. (2021) has provided suggestions of direct interventions for engagement and social interaction. Indirect interventions are achieved by removing barriers to interaction with others, such as ensuring hearing aids are operational and eye glasses are cleaned and positioned properly (Curelaru et al. 2021, p. 951). When staff conceive of every activity from personal care to leisure as focused on interaction within caring relationships they become "communication partners" (Ellis & Astell 2017). Creative facilitators of activities foster a relaxed and safe environment that includes everyone, encouraging them to participate and interact with others. Therefore interaction and relationship building become positively synonymous with any activity through the day. The person's participation, if they so choose, stimulates their responsiveness and their embodied abilities and capacities to socialise with others.

This study concurs with the earlier findings of Campo and Chaudhury (2011) which discerned that the built design of aged care homes is a significant precursor to promoting interaction and relationships between people. The provision of pleasant places to sit, perhaps with appropriate background music playing and no television noise, means people have ready-made venues to congregate, interact and develop relationships with one another. In this study many people chose to gather together and interact around carefully arranged tables and in lounge chairs. Some people were observed relating with those in comfort chairs, such as holding their hand and chatting. This pattern indicated a relaxed, inclusive and amiable pattern of being together, interacting and caring for one another in inter-dependent community. As a counterbalance, I observed the provision of their own room, gardens and smaller rooms where the person could retreat and rest in solitude and quiet (Fleming, Zeisel & Bennett 2020, p. 54). I suggest that insufficient space, and pleasant places such as courtyard gardens and smaller sitting rooms, as well as time out and rest from others, may precipitate the enacting of aggravation and conflict between people in communal places. People need and appear to choose their own space and solitude, or socialising through their day.

In further describing how people in this study enact their voice I now consider the importance to the person of developing relationships with other residents and staff members, and in maintaining relationships with their family members.

9.3 Inclusion of Voices in Relationships

The findings have emphasised the importance of acknowledging each person in their personhood, This means respecting, recognising, responding to and developing relationships situated in slow, comfortable and informal interchange. In reaching out to engage and form relationships, the person appears to express their innate need for connection with others, residents, family and staff members. In connecting with others they each express and/or enact their voice, to continue to make their contribution as a valued participant in relationships.

Relationships with each other

This study concurs with previous research which found that people with advanced dementia form and develop relationships with one another. Relationships occur as a result of the familiarity fostered when people are often together in daily activities and meal times, and as they sit in shared spaces (Saunders et al. 2011). Relationships of mutual appreciation, trust and companionship, meet many people’s social needs (de Medeiros et al. 2011). The current study revealed that some people, including those with predominantly non-verbal language, chose to form friendships and spend time together and interact intermittently. This study also found that some people who walked around the home would spend time sitting and relating with people in comfort chairs. Their congregating demonstrated their appreciation of and trust in one another (Kontos, P, Miller & Kontos 2017). This form of interacting is perhaps reminiscent of former times when people shared around the table in meals and refreshments, or friends joined together and socialised. These occasions demonstrate the relaxed, inclusive and amiable pattern of being together in inter-dependent community. Like the study of Doyle, Rubinstein and de Medeiros (2015), the current study presented numerous examples of people enjoying being with one another. Such times encourage people to enact their voices with confidence and vitality, and support one another in sharing humour, words and/or gestures and turn-taking.

Praxis implications

The person's day needs to be premised from beginning to end on relationships and interactive activities, as well as periods on their own to rest and sleep. Carers assisting each person to get up in the morning and throughout their day may engage in some pleasantries through: explaining what they are doing with the person; encouraging their participation; and interacting about a subject they know is relevant to the person. Then the person is more able to express and/or enact their voice in their interactive responses, agency and identity. Unless a person is unwell, needs a rest day or prefers to be on their own, assisting them to get out of bed and dress means they are invited to spend parts of their day with others. In so doing the person has opportunities to participate in communal life, interact with others, and form relationships. Thus the person realises intrinsically that their presence and participation amongst others is significant and meaningful. The person's position and their voice, be it verbal or non-verbal or a blend of both, is vital and central to who they are, and to the daily communal life in the aged care home. The importance of people interacting and developing relationships with one another necessitates creating pleasant and accessible places for them to gather. Relationships with family, and friends who have become family, are also important in encouraging the person's voice and sense of well-being.

Relationships with family

This study has discerned the value many people give to their relationship with family. Similarly, Walmsley and McCormack (2017) determined that people with advanced dementia retain peak awareness and engagement during interactions with family members, indicating the significance to the person of their family's continuing presence. Furthermore, Walmsley and McCormack (2017) also found that the person is aware of when their interactions with their family are in-step, in harmony and so they experience well-being. When interactions are out-of-step the person evidently feels overlooked and socially frustrated. The current study has extended this research of Walmsley and McCormack (2017) by identifying that many people retain the ability to remain engaged in their family member's conversation. The person's apt gestures and words have evidenced their ability to follow the content, emotionality and tone of their family member's speech and interpret their meaning. The person may also extend, exemplify or even correct their family member's wrong assumptions, as was demonstrated on several occasions in this study. The person thereby contributes to the conversation, enhancing the understanding of others with their insights. In their responsiveness the person may enact their deeper awareness, love and empathy with the feelings of their family member by expressing their care. The person may also express their love and affection through mutual kissing, hugs and holding hands, demonstrating that these embodied acts continue to be meaningful and needed by the person and their loved one/s. The demonstrations of these intact abilities by several people during the current study suggests that the opposite may occur. At times the person's insights and contributions may not be given opportunity and time to be expressed, and are overlooked in the course of interactions with family or staff.

During this study I have heard and observed that many family members visit regularly to actively support their relative's communicative and interactive capability, as part of ensuring their well-being. Family members spoke of and were seen using creative companionable ways, appropriate to the person's needs and interests, to engage them in verbal or non-verbal interaction. These stimuli included listening to and joining in favourite music and songs; looking at and reminiscing with their family photograph album; doing an activity together, for example colouring, going for a walk or sitting in the garden together; reading poetry or stories to them; and engaging in personal care, such as shaving them, painting their nails, hand massage or styling their hair.

According to O'Rourke et al. (2018), lack of familial contact often causes the greatest expressions of loneliness and grief in the person, as was discerned in several people in this study. This study has shown that people with advanced dementia display despondency and low mood due to their loneliness and need for the company of their family. Some people are able to articulate their need for a specific person. This study found that missing their loved ones with whom they have shared long-term significant relationships may demonstrate an unrecognised and unmet need in some people. This study found that some families only visit their relative occasionally, and some family members no longer feel able to come, due to their perceived difficulties in communicating with their relative. Another recent study has found that the person's familial relationships are affected when family consider that their relative's memory and communication have changed. As a consequence families may assume that the person has lost their entire capability to communicate and even their personhood (Hennelly & O'Shea 2022). Families may not realise that decreasing visits or withdrawing creates a palpable relationship and interaction vacuum for those people (O'Rourke et al. 2018). The person may enact their awareness of this by receding into sadness, silence and social isolation, even losing their capacity and desire to interact (Curelaru et al. 2021). Moreover, when visiting is restricted in aged care homes, for example during Covid-19 pandemic outbreaks, residents experience an exacerbation of social isolation, depression and cognitive decline (LeVasseur 2021). Some aged care organisations have implemented alternative ways of connecting, for example via the on-line space. But for many people, virtual connections are problematic and no substitute for being physically together.

Praxis implications

The challenging circumstances described above lead to the person sensing the absence of family. Despite the mandatory restrictions due to Covid-19 regarding socialising, there remains a call for relational and social interactions and activities with family in whatever creative ways are possible (Curelaru et al. 2021). Interventions to support and nurture the family's ongoing relationship and engagement with their relative would be beneficial. Referral to a designated person such as a pastoral carer/ chaplain or similar, or a community organisation such as Dementia Australia or Alzheimer's Association, could support family members in their experience of ongoing grief concerning changes in the person. In addition, targeted education programmes may assist families to understand the person's voice repertoire and develop their interactive skills to be "in-step" with the person's intact communication capabilities, enhancing their relationships and time together (Walmsley & McCormack 2017). Positive interaction by families with their relative means appreciating the person's voice as relationally meaningful, rather than necessarily comprehending its content. In-step interaction by family elicits "harmony, spontaneity and reciprocity", rather than out-of-step non-engagement (Walmsley & McCormack 2017, p. 626). In this study many family members indicated their need and openness to learning more about how to support the person's voice and their interactions.

People living in an aged care home spend the majority of their lives with staff and the frequency of their family's visits varies. Therefore, it is reasonable that their significant human needs to interact and share love and affection be provided by staff.

Relationships with staff and praxis implications

The significance of relationships between the person and formal caregivers remains an ambiguous notion in the residential aged care setting (Barnes & Brannelly 2008, p. 389). The anecdotal view by some staff is that they should not form relationships with residents. However, this study's findings concur with other studies (Barnes & Brannelly 2008; Haunch, Downs & Oyebode 2022) that staff members often build relationships with people and their family as a result of being together in intense and ongoing situations in this phase of the person's life. Keller and Kittay (2017) emphasise that "the privileged access to the other's thoughts, feelings, cares, and concerns" necessitates relationships and responsibilities as part of staff's ethic of care (p. 542). This study confirms that acknowledgement and inclusion in a community of relationships enhances the sense of self-esteem, belonging and well-being of people with advanced dementia, and those who care for them. The experience of inter-dependent relationships and belonging in community meets the person's deeper spiritual needs. Inter-dependent relationships are "a living out of our true humanity", resonating with the theological reflections of Swinton (2012a, pp. 278-9). These continual relational experiences promote the person's expressions and enactments of their voice. The relational connection between the person and staff member does not just happen but results from intentional care praxis. The pattern of “slow” care praxis as opposed to rushed care, is described as “being in the moment, doing one thing at a time, and creating joy and contentment” (Lillekroken, Hauge & Slettebø 2017, p. 944). This praxis means staff enact an ethic of care shown in their commitment to developing relationship with the person. Developing relationship, as described by carers in this study, means being finely attuned, attentive and trustworthy to each person by enacting:

> *respect, rapport, being flexible, going with the flow of each person…use their name, involve them, speak well to them, connect with them carefully (AT, SI, PC, Home 1, Carer Annabelle, 5/03/18).*

Careful praxis is balanced between two premisses: staff being attuned and attentive to the person’s voice in initiating and responding; and staff being self-aware of their own attitudes and actions in their regular person and relationship-centred care of the person. As staff have reiterated in this study, care is premised on knowing the person, and knowing themselves and being self-reflective. This knowledge includes knowing each person’s voice repertoire, both their communication abilities and their personal characteristics of agency, identity and storied-life. Keller and Kittay (2017) describe this as a “bottom-up” moral approach to care. Rather than applying general principles, this approach necessitates forming and being in relationship with each person. Thereby staff do not just know about the person but know them closely, through the nature of their caring relationship, and being informed by the important details of their storied-life (Keller & Kittay 2017, p. 542).

On the other hand, as relationships develop and deepen, the person’s awareness and observation may mean they constantly notice particular staff passing by and may seek connection with them. The person sitting alone may reach out to engage with someone who will stop and relate with them. Staff can demonstrate their respectful acknowledgement through eye contact, stopping and listening, and showing interest and engagement through appropriate questions and comments and bodily and facial gestures. The building of trust through staff being attentive, attuned and reliable promotes the person’s sense of self-worth and confidence in a staff member’s reliability. The person then also senses the opportunities they have to voice themselves in this receptive and responsive relationship with the staff member (Ericsson, Kjellstrom & Hellstrom 2011; Watson 2019). These encounters become meaningful moments shared together (Hillier & Stokes 2012). This study has concurred with that of Douglas et al. (2021) that people are aware of the attitude of staff when they are assisted to eat during mealtimes, and also at other times of interacting. If the staff member relates with the person, interacting with them cheerfully and empathically, there are numerous positive ramifications for the person. They are more likely to eat, eat more, or willingly engage in their personal care. They become more responsive and expressive with their voice during their diverse daily care and other interactions.

In this study many staff have described and demonstrated skilled and intuitive care as attending to the person. Staff have described and exemplified calmly and carefully “putting oneself in their shoes”. This approach to care is encapsulated in the conception of empathy. I have already described empathy being expressed by people with advanced dementia. Empathy is an expression of agape, a Christian term for deep God-like love as

> *…an extension through the imagination into a [person’s] inner world of experience. It requires being receptive to the pain and distress that the person displays and speaks about… Compassion also involves feeling-with… Compassionate receptivity to the suffering of the [person] drives a decision to extend oneself in order to alleviate it (Pembroke 2019, p. 133).*

Such empathic care by staff means that they imaginatively feel beyond themselves and feel “with” the person. In so being they become receptive to the person, communicating that they are hearing, understanding and responding with respectful care and the desire to ameliorate their distress and/or enhance their well-being. Adversely, “care done without the right affect, such as love and empathy, is often not experienced as care at all” (Keller & Kittay 2017, p. 542).

The need of the person to have and to hold embodied love and companionship continues to be voiced in this last phase of life. In this study several people with a storied-life of nurture and care engaged in nurturing a companion, such as a teddy or doll-baby. The person also initiated interactions with others through their companion. Companion therapy requires the training, acceptance, respect and facilitation of staff whereby interaction between the person and their companion is promoted and not diminished (Mitchell, McCormack & McCance 2016). Parsons (2022, p. 265) writes of “the expanse of the forever self”, that we continue to be the essence of who we have always been. People, pets, objects of nurture and rituals that are familiar, loved, and reminiscent of comfort, love, relationships and home, hold a person in their identity like an anchor (Lindemann 2010).

The relational interface between each person and staff displays the extent of shared emotions and inter-dependence, resulting from common human experiences and relationships with each other. Based on this study’s findings, I provide a table of suggested guidelines below which could be used for establishing and enhancing relationships one-to-one, and in smaller and larger groups.

Table 7 Recommendations for Establishing and Enhancing Relationships

One-to-one interaction, small activity groups, larger gatherings as appropriate: to show recognition, respect, responsiveness, relationship and well-being
Come alongside the/each person gently and greet them by name with genuine warmth
Ask the person permission to be with them in their place or invite them to the activity
Explain why you are there and/or what would like to do with them
Ensure the person's sensory challenges are catered for- hearing aids with batteries, glasses clean and both positioned correctly, in a well-lit room with no sunlight glare and no intrusive noise
Be self-aware- present, attentive, attuned, appreciative, and calm in verbal tone and body language including eye gaze and touch as appropriate
Remain focused on each person's responses, their engagement, expressions and enactments
Ask creative questions, with prompts of person's possessions/story/comments or gestures
Use your knowledge of the/each person's voice repertoire
Listen to the/each person's words and notice their non-verbal gestures and mirror them
Enlist the/each person's involvement with courtesies and positive comments
Respond to the/each person's initiatives with supportive comments
Acknowledge and include the/each person's capabilities and capacities
Follow and support the/each person's pace, turn-taking and level of engagement
Affirm the/each person's reciprocal care and responsiveness
Use upward inflection to indicate questions and interest
Indicate your imminent departure to the person/ the group slowly in change of tone
Enact with the person appropriate courtesies of farewell

This list may also provide a guide for family members in relating to their loved one and encouraging positive relationships and in-step interactions.

Voice enacting contribution and reciprocity

During this research it became clear that people responded warmly to other residents and staff with whom they have formed relationships. As has been found previously the provision of dedicated time, attentiveness, empathy, compassion, and reciprocal relationships indicate that the person is aware and invests themself in these relationships (Allison, Balbino & Covinsky 2019; Perkins et al. 2015). This approach to care is especially significant when familial relationships are not always available or fractured. The person enacts their particular voice repertoire, such as turning towards them, waves, smiles and other facial gestures, nods and hand movements, words and sounds (Douglas et al. 2021). As evidenced in this study such connection is transformative for the person, enlivening them, giving them a sense of their worth, their meaning and purpose. The person senses they belong in this community.

In this study there have been situations of the person with advanced dementia showing empathic understanding, hospitality, encouragement and care voiced to others, residents, staff and family members in reciprocal relationships. Some people, consistent with their storied-life, become aware of, and pay attention to another's distress or need for companionship and offer support to them. Pembroke (2019, p. 141) explains empathy as "a feeling with" through "an imaginative projection into another's inner world of pain and distress". Being cared for by one's friend in their gestures of support confirms to the person that they and their concerns matter, and demonstrates the tacit effects of inter-dependent community. Such relationships acknowledge that each person has the deeper need, which I define as spiritual, to give as well as receive in relationships through building trust, rapport and deeper connection with others (McFadden, S & McFadden 2012, pp. 77-8). Reciprocal gestures, familiar and performed over a lifetime, remain embodied characteristics in many people. In giving to others, the person is voicing that they still desire to help others, make their contribution, and positively affect the world around them. I reflect again that this is what gives meaning and purpose to daily life. Through mutual acknowledgement of personhood, inter-dependent community and citizenship each person, family, friends and staff have a part to play.

Praxis implications

Fulfilling their need to care provides the person with a sense of their value, meaning and purpose in their daily life amongst others, and demonstrates their personhood in interdependent community (Kontos, P, Miller & Kontos 2017). In a theological sense in their expressions of reciprocity and care the person enacts being in the image of God who seeks out human-kind to freely establish loving relationships (Hudson 2016, p. 51). The repeated occurrences of reciprocity in relationships in this study counteracts the stereotypical view of others, including some health professionals (Gove et al. 2017), that people with advanced dementia are emotionally absent and not capable of responding or reciprocating in interactions and relationships. Such presumptions perhaps reflect that some professionals spend limited and infrequent time with people with advanced dementia, and may not develop relationship with them. Therefore, as has been identified in this study, the person would be less responsive to them.

The praxis of noticing and receiving with gratitude the person’s acts of kindness and care affirms their contribution. Reciprocity in relationships goes some way to redressing the power imbalance that exists within aged care homes (Killick & Allan 2010, pp. 39-40). Such reciprocity affirms the person not only as a care recipient but also as having continuing capabilities and capacities to care for others, those people they live with, their family and friends and staff. There is a deeper intuitive level of communicating, voiced in the interchange of reciprocity between people, which appears to affirm them, encourage well-being and lift their spirit. Equally, when the person knows through their lived experience that others will be attuned and acknowledge their voice, they receive affirmation and reciprocal relationships develop (Hennelly et al. 2021). Such is the cyclical nature of inter-action, mutual connection, affirmation and relationships with one another. This study has confirmed the context of relationships as providing opportunities for meaningful engagement with people with advanced dementia and their having opportunities to voice.

The next section discusses how and why people display in their voice their personal identity, characteristics, agency, and ongoing storied-life, in their voice repertoire. There is also discussion of how family and staff may encourage these aspects of the person.

9.4 Voice Enacting Agency, Identity and Storied-life

Several previous studies have recognised that people with advanced dementia continue to enact their personal characteristics of their agency (Cahill & Diaz-Ponce 2011; Chaudhury et al. 2017), their identity (Batra et al. 2016; Perkins et al. 2015; Schneider et al. 2019) and their storied-life (Berendonk & Caine 2016; Vigliotti, Chinchilli & George 2019). This study has elaborated on earlier research which discerned that the voice of the person demonstrates the close association between their agency, identity and story (Kitwood & Bredin 1992; Moos 2011; Nicholls et al. 2013). The themes described in this study, particularly in Chapter 7, highlight that the person’s voice is an intact, continuing thread of the interwoven motifs of the person’s identity, agency and storied-life, enacted in their interactions and relationships. In articulating their agency, the person also often voices their desire to maintain their unique identity. They may also narrate something of their story, regarding their history, needs, lifestyle preferences, and opinions. Concurring with previous research, in this study people with advanced dementia have expressed a continued sense of their self, articulating this in narrating their storied-life with others according to their communication abilities (Godwin & Poland 2015; Perkins et al. 2015). For example, at times the person has demonstrated their level of awareness and agency in critiquing their positive and negative experiences of staff practices. The person may display either their appreciation or disdain in observable or audible ways. Thus they may critique staff behaviours and practices that overlook, frighten, ignore, or seek to rush and control them. The ability of people with moderate to advanced dementia to be aware of and critique service delivery and staff practices is not a new finding, having been identified by Goldsmith (1996), Kitwood (1997) and Sabat and Harré (1999) much earlier, and also later by Cahill and Diaz-Ponce (2011). However, the current study advances this knowledge by demonstrating that the person's critique may be according to the person's past and continuing performance of their essence, identity and their storied-life. Their critique of negligent and deficit staff practices then becomes the person's counter-narrative arising from their own alternative attitudes and approach to living their life in respectful relationships to others.

This study has extended the findings of Ward et al. (2016) to include women with advanced dementia regarding their attention to their appearance. In continuing to pay attention to their appearance these women enact their agency, storied-life and their identity or sense of self. As observed in this current study these women also “resist being overlooked” by their family and staff (Ward, Campbell & Keady 2016, p. 406). For some others in this study, their sense of identity is based on their career and continuing to display the personal attributes of their leadership or authority and personality. Still others reminisce with their agency about places and people that continue to have relevance to their sense of identity. This notion of the person's voice as enacting their identity and storied-life through their agency extends the continuity theory of Atchley (2003) to people with advanced dementia. Continuity theory recognises that the person retains those aspects of their storied-life most important to their identity and spiritual well-being. They do this actively with their agency, making decisions to seek out places and engage in relationships and activities with others to confirm their continuing sense of their identity and their ongoing storied-life. This study extends that of Boyle (2014) to include people with advanced dementia as often voicing their agency creatively. In this study I observed people exercising their agency and expressing their identity with strength and creativity, sharing humour and laughter (Moos 2011), an embodied gesture or their words (Kontos, P et al. 2017), and extended narration of their storied-life in words and gestures (Hydén 2013).

Previous research by Berendonk and Caine (2016) focused on the accounts of care staff who were found to place greater weight on the veracity of stories of family members about the person. Their research considered that this approach of staff diminished the importance of gleaning their storied-life within relationships and listening and observing with the person directly. In this study the central participation of people with advanced dementia meant they expressed and/or enacted their stories first-hand. As a result many people expressed and/or enacted pleasure, meaning and the deeper significance in the present through their reminiscence, also reported in the study by MacKinlay and Trevitt (2012). Secondly, as found by Hydén (2013) and Milne (2011) some people “perform” a former event of their storied-life of a similar nature to their present experience and emotions as a creative way of working through their current crisis and state of well or ill-being. Thirdly, some people narrate an aspect of their storied-life in a single word, phrase, or gesture, responding to a sound or a sight in the present, whereby past feelings and thoughts might surface (Frank 2013; Josephs 2002, p. 162). Fourthly, the person's reenactment of their past story of trauma may be a particularly painful embodied experience of suffering and/or loss and grief. The person's sharing of their story is significant, becoming a testimony to what and who has been, and may remain important to the person (Berendonk & Caine 2016). One of the central participants in the current study provided a surprising discovery that I had not found previously in the literature. Paul was able to visualise the scene of his past life as a sea captain on his ship as he looked through the window as his existential lived experience which he connected with and described in vivid detail (see Extract 7.44). Therefore, I propose that reminiscence is about remembering the past, and also for some people about living this history existentially- yes, in the here and now.

Praxis implications

Seminal texts on personhood reveal that the performance of their agency, self-identity and storied-life are crucial to a person's "sense of self-worth and social confidence" (Kitwood & Bredin 1992; Sabat 1994, p. 14). In this study staff showed how they assume the position of caring holding, particularly when family and friends are absent (Lindemann 2010). This is an important aspect of an ethics of care framework. Caring holding relies on staff recognising a person's agency and identity, scaffolded on knowing some significant details of their storied-life that have shaped them. In this study several staff spoke of how they actively seek this knowledge with the person and/or their family, and by reading social-spiritual care plans. Such knowledge aids staff in promoting reminiscence in their ongoing interactions with the person (Hydén 2013). Furthermore, while requiring situated verification with the person, this knowledge gives staff relevant content to provide support appropriate to the person's needs, choices and preferences (Godwin & Poland 2015; Watson 2019). As staff provide their attentive listening presence, gentle touch and as appropriate a hug, practical support and affirmative responses, they acknowledge the person voicing their continuing agency, identity, and storied-life. These responses are respectful of the person and recognise their need for this support, while also acknowledging their interdependence with other residents and staff as a citizen participating in the ordinary activities of their daily life in this community (Gjernes & Maseide 2020).

This study has confirmed that family members play a crucial supportive role in responding to a person's voice and helping them enact their agency, identity and storied-life in their own way. In this study family members spoke of their role in being custodians of the person's story (Koch & Crichton 2007), remembering and reminding their relative of their story as they reminisce together verbally and non-verbally (Palmer 2013). Family members also have represented the person's story to staff to encourage their understanding and responsive care of the person. The support of family and staff members may become a stabilising anchor as the person experiences other personal changes, lessening their anxiety and building their confidence in their continuing identity.

Person’s reactive responses to others’ positioning

As demonstrated in this study, the person continues to express and enact sadness, frustration and negative emotions during this phase of their life. The various reasons for displaying such emotions were found to be similar to those described in previous research. Some people may be expressing their embodied personality trait or past working role, such as taking leadership and being in control (Berendonk & Caine 2016). Conversely the person may feel at times that they are controlled or coerced by another (Douglas et al. 2021). The person may be affected by their particular internal physical, emotional or spiritual issues (Watson 2019). They may be reacting to distressing and difficult external interactions, incidents or events existentially or in the past (Cameron et al. 2020; Douglas et al. 2021). Unmet needs for social interaction or meaningful activities may affect the person (Cohen-Mansfield et al. 2015). Moreover, the person may be unable to develop relationships or experience conflict with some others, causing them sadness and negative emotions (O'Rourke et al. 2018). As is the situation for people living in other settings of close communal living, relationships are not without their challenges for people living with advanced dementia in residential aged care. The combination of the diversity of people, the close communal living as well as working environment, and challenges for people in health and well-being, create complexity and compromise, conflict as well as companionship (Hudson & Richmond 2000). As identified by Mok and Muller (2014), close proximity for some people prompts conflict and at times aggression between them.

Most of the staff who were interviewed understood the various reasons why a person may exhibit responsive or reactive behaviours. However, not all staff members were able to describe how they facilitate the person to express their needs and concerns and provide situated support to them. Due to their training within the organisation many of the staff emphasised the need to be self-aware of their words and actions, and recognised their consequential effects on the person. However, judging by the comments of several leaders, controlling and rushed behaviours were still enacted by some staff resulting in the person becoming aggravated and at times aggressive. In this context of emotional labour and at times diminished staff resources, there appears to be the ongoing need to mentor and train staff in their values, behaviours and attitudes to be affirming of personhood and supportive of each person’s capabilities and strengths. However, during the fieldwork in becoming aware of my own behaviours on occasions, I realised how easy it is to be careless in my positioning and become complicit with stigmatising behaviours in interactions with the person. Behaviours such as overlooking or ignoring the person, their presence, participation and contribution mean they are excluded. The person is impacted by these behaviours and expresses their resultant responses or reactions. In this busy, interactive and complex setting with so many diverse people with multi-faceted lives and needs it may be easy to get swept up in the ongoing dialogue and neglect to be focused on each person.

Praxis implications

Of crucial importance is being reflexively mindful since this approach facilitates the researcher and each member of staff in enacting an ethics of care. This moral commitment prompts divesting self of power and control, and facilitating the person's recognition, inclusion, participation, contribution and flourishing.

Returning to being self-aware and reflexive are important strategies to maintain both researcher and practitioner ethical equilibrium and responsiveness. Knowing the person and their personal characteristics enacted in their voice repertoire enables staff to relate knowledgably and calmly to them, rather than misinterpreting them or attempting to control their actions. It is possible that some significant details of each person's life and identity may be overlooked. Yet these details become the matter with which to facilitate our interactions and relationships with each person. Hence those details need to be recognised and emphasised, keeping staff aware of their importance for encouraging interaction and relationship with the person.

When staff consider the interpersonal dynamic occurring in the person's expression of their behaviour, be it positive or negative, this adds a layer of complexity. Yet, this understanding aids in appropriately understanding the person's negative reactive responses. Some people may need to be supported by staff to navigate away from others with whom they have difficulty, towards activities and other people for positive interaction (O'Rourke et al. 2018). Thereby staff may be able to actively resist stereotyping people with advanced dementia as simply "experiencing behaviour changes that may escalate and include aggression" (WHO 2020). Staff knowledge of the times and various causes that disturb the person's equilibrium, and also how and when to reframe the person's negative behaviours as reactive responses, are important insights to guide staff in their care. In developing skills, staff can better recognise the person's non-verbal cues of struggling with physical, emotional and/or relational concerns, or experiencing ill-being.

As demonstrated in this study some people may need to be supported by staff with specifically tailored interventions. These strategies support people to inhabit, share and move through places without confrontation, and to have separate places and activities that provide them with meaning, purpose, and well-being. In addition Killick and Allan (2010) have emphasised:

> *Discoveries in the art of communication in dementia have found that a person's challenging behaviour and disturbed language and nonverbal expression, rather than being due to brain damage, is actually the result of the deprivation of opportunities for real communication (p. 19).*

If staff fail to communicate with the person through listening, engaging and responding to the person, staff denounce their personhood and diminish a person's confidence and ability to communicate. The absence of actual communication with the person may result in neglect of the person's needs (Slape 2019); their feeing rejected and lonely (Lombard 2021); their mirroring staff's agitation and aggression in their reactions towards others (Cameron et al. 2020); and/or the person becoming silent and withdrawn (Palmer 2013). In positive interactions with staff which encourage the person's capabilities, capacities, inclusion and participation, the person is more able to express their identity and agency in their choices and preferences. When staff exhibit positive reflective praxis by expressing an appropriate positive touch, hug, caring gesture, or facial expression along with their words they express encouragement, affirmation and relationship to the person. With regard to reassuring family of the person's lived experience, staff could, with the appropriate privacy safeguards, send photographs to their family of their relative engaging in positive interactive events with others. This would give families a more balanced, realistic and positive perspective of their loved one's expression of their voice, and experiences of interactions and relationships with others. This innovative support could act as a counterbalance to the mandatory informing of families when negative incidents and issues occur.

Supporting emotional pain and grief

As relationships develop with certain others and/or at certain times of the day, the person may voice their deeper and more painful feelings about their lived experience (Alsawy et al. 2020). The current study demonstrated the person expressing their unmet needs, unresolved grief and unfinished regrets and shame, according to their voice repertoire with a trustworthy and attentive staff person. In telling their story, past feelings and thoughts of embodied grief continuing into the present might surface (Frank 2013; Josephs 2002, p. 162). Previous narrative research with people with advanced dementia found that the person's enactment of their storied-life may have relevance to, and even become, the medium by which a person works through ongoing issues of transition, grief and identity (Hydén 2013; Hydén & Örulv 2009). This study elaborated on this earlier finding in identifying three specific circumstances in which the person expressed and enacted their existential trauma.

Firstly, for some people coming into an aged care home is extremely difficult and distressing (see Extracts 7.12, 7.47). They may feel ill-prepared, uncertain, fearful or anxious, lost, abandoned and lonely. Family members may also feel exhausted and distressed. The entire situation is laden with all kinds of grief, loss and change. The person may express and/or enact an earlier story of trauma which resonates with their existential experience of trauma of moving into an aged care home (Hydén 2013).

Secondly, the late afternoon can be a time of unsettlement for the person with advanced dementia, known as "sundowners" (Nowak & Davis 2007). As the sun goes down and they prepare for night, perhaps there is a latent familiar and embodied rhythm within each person that this has always been their time for gathering together with loved ones in their home after the day away from each other (see Extracts 7.12, 7.13). This is the time when the person may voice their need to return to home and connect with significant loved ones, those constant and reassuring anchors through the person's life (Fukui et al. 2011; Norberg, Ternestedt & Lundman 2017).

Thirdly, the person may articulate, in words and gestures of sadness and distress, that they are missing someone or some entity in their past life. They may also enact their sadness and/or distress in their facial gestures, verbal tone, their silence or their calling out, or in expressions of frustration, aggravation and enactments of what may appear to staff as aggression. These grief responses to particular forms of loss in the person's life can become complicated for people with advanced dementia. Accumulated grief from various forms of past losses has been identified as part of many people's lived experience (Kontos, P et al. 2017). Concurring with Godwin and Poland's research (2015), in the current study several people enacted their grief as vivid and existential (see Extracts 8.6, 8.7, 8.9). This finding indicates that the person may experience ongoing and sporadic intense periods of grief for their spouse and significant others who have died, and also for valued places and past experiences. During such conversations I have discerned that these emotional experiences may be likened to that of "ambiguous loss", defined and described by Boss (2010, 2016).

Pauline Boss is a leading family therapist recognised for her development of the theory of ambiguous loss. Boss determined that ambiguous loss is a significant cause of ongoing stress in individuals, families and communities. She defined this generally as "an event or situation of unclear loss (often in traumatic circumstances) that has no closure" (Boss 2016). Ambiguous loss may be experienced in one of two ways, either as the psychological presence but physical absence, or the physical presence but psychological absence of the loved one or entity (Boss 2016). Boss has applied the concept of ambiguous loss to the grief experience of family care givers of people with dementia. Many family members experience the physical presence but psychological absence of their loved one with dementia. However, I extend Boss' definition of ambiguous loss to include the way in which people with advanced dementia deal with their fears, grief and loss. When the person senses they have lost the physical presence of their loved one, or some other significant aspect such as their actual hometown or capability, they may still experience this person or entity as psychologically present. With challenges in sequencing time and discerning actualities, the bereaved person with advanced dementia continues to search for the person or entity to reconnect physically as well. Thereby their feelings of grief in sadness, guilt, uncertainty, and stress never resolve completely. As evidenced in this study sometimes the person may even experience the lost person, their lost ability or place, as actually with them in the present.

Praxis implications

Knowing the person's storied-life includes a specific awareness of their experiences of trauma, grief and loss. When staff have this knowledge and are trustworthy and attentive to each person, they develop relationships that may deepen over time. Being respected and responded to in relationship seems to build the person’s confidence, trust and openness to respond and share their deeper needs, concerns and meanings. The person senses they will be listened to, and validated with respect and affirmation (Kitwood 1997, p. 91). Concurring with previous research this study found that challenges to spiritual-emotional care may be due to staff and family being reticent and/or not equipped nor appropriate to engage in such care. This reality may necessitate referral to a therapeutic practitioner with specialist training, or providing the staff directly caring for the person with specific strategies to support the person during a reactive episode. Therapeutic relationships can support the person to voice their complicated loss and grief (Boss 2010, 2016). This care may help the person to release pent-up emotions, become adaptive, and experience periods of pleasure and peace through connecting in relationships and their daily activities (Boss 2016; Harrington, Williamson & Goodwin-Smith 2018).

Staff may feel they are too “busy” and rushed (Harrington, Williamson & Goodwin-Smith 2018), to read Social-Spiritual Care Plans and, more recently introduced, Behaviour Support Plans (Aged Care Quality and Safety Commission 2022a). These plans have been compiled with due diligence of careful assessment and documentation of appropriate strategies. In this study it was apparent that not all staff were knowledgeable of their content. This information while necessary, is often circumvented in what is deemed a time-poor, demanding and exacting work environment. When staff recognise and understand the person’s prevalent responsive and reactive emotions and needs, they are better able to provide support within their role designation, capability and capacity, and also arrange appropriate referral. The provision of empathic listening presence is a feature of spiritual care that responds to the person’s deeper needs to be heard and understood (Pembroke 2019). This care alongside the person in their times of voicing their emotional pain and distress, grief and loss sadness and distress provides “a holding place” of a “homey” environment within companionship, wherein the person can express or enact their feelings (Fukui et al. 2011; Lindemann 2010; Simpson 2006). Such care can make all the difference to whether the person experiences shalom (see Section 4.2 Strength-based inquiry) and gradually feels “at-home” (Simpson 2006). When the person feels “at-home” they are more able to voice themself in their various personality traits. As they continue to live in the aged care home the person will continue to adjust, at times to major changes within themselves, their circumstances and those around them. Therefore, their need for “a holding place” of supportive relationships, empathic listening, and calming reassurance will continue throughout their life in the aged care home. Staff need to be as well-prepared as possible with empathy and compassion, as well as skills and knowledge, so they can be alongside the person and facilitate their journey.

The necessity for the person to continue to enact their deeper needs, make deeper connections and be supported in this last phase of their life, highlights the importance of the nurture of their spiritual dimension discussed in the following section.

9.5 Nurturing the Person's Spirituality through their Voice

This study has evidenced specifically that the person with advanced dementia continues to voice their connection with who and what is important to them and gives them a sense of meaning and purpose. This finding concurs with the research of Harrington, Williamson and Goodwin-Smith (2018) which focused on older people in residential aged care generally, and their definitions of spirituality as "connections". The person expresses the significance to them in maintaining these connections through their agency in choosing to be present and participate in one-to-one support and particular activities. These connections may include the diverse forms of relationships with others and/or God, the natural environment, religion, and/or of the various arts (MacKinlay 2006, pp. 14-5; Meaningful Ageing Australia 2016). Such experiences provide opportunities for interaction and relationships. In this study several people voiced in their words and actions the significance to them in being present and connected. Thus the person testified to their ongoing self-worth, participation and contribution in the world, in stating, "This is me". In this study their voice has been discerned as the means by which the person articulates or enacts who or what is important to them, as an aspect of their spiritual dimension. Their voice, according to their unique repertoire, is also the person's means of engaging with those important aspects in their life and sustaining those deeper connections that continue to give the person meaning, purpose, and a sense of well-being in this latter phase of their life.

Praxis implications

Spiritual care of people with advanced dementia is focused on their personhood and/or being in the image of God. Such care is also person and relationship-centred, responsive to the person's spiritual dimension as an intrinsic aspect of their holistic needs, including: to have value and significance; to have a sense of meaning and purpose; to experience peace and hope; to love and be loved; to give and receive; to enjoy beauty and wonder; to reminisce and review one's life; to value religious faith and beliefs or transcendence; to be creative (Harrington, Williamson & Goodwin-Smith 2018; McFadden, S & McFadden 2012, p. 144). Rather than coming to a place of "narrative foreclosure", defined as the person having no further possibilities for meaningful engagement, nothing to look forward to, and nothing to add to one's storied-life (Bohlmeijer et al. 2011), the person discovers fresh opportunities to express and enact their voice. Resonating with the findings of Perkins et al. (2015), in being together with others, and/or enjoying one's solitude, and connecting with meaningful activities and relationships, the spiritual dimension of each person with advanced dementia continues to be nurtured. The person continues to find meaning, purpose, and self-worth in the present.

Spiritual care provides one-to-one listening and observing, with compassion, empathy, support and reassurance. In circumstances of grief and loss, trauma and other distressing experiences, a spiritual care practitioner, a staff member in various roles and/or a chaplain may provide listening, empathic and compassionate presence to the person. They may also recognise when to refer the person for further help from other members of the multi-disciplinary team. The provision of other spiritual resources, if appropriate to the person, such as prayer, meditation, worship gatherings and other faith rituals, facilitates them in coming to a place of finding the ultimate meaning for their life with a sense of rest and peace (Camacho-Montaño et al. 2021; Hudson 2016; MacKinlay 2006).

An earlier study by Schneider et al. (2019, p. 1731) was with one woman with advanced dementia who had previously expressed “minimal verbal expression”. As this person engaged in a personally meaningful activity of viewing artworks in an art gallery this enabled deep connections for her. During her viewing, this woman was able to engage in a lengthy turn-taking conversation with her skilled and empathic gallery guide regarding the artwork (Schneider et al. 2019). My study resonates with this finding. I developed relationships with several people who were assumed by staff and family members to have minimal, incomprehensible, or no verbal expression. However, during one-to-one interactions, each person demonstrated their verbal capability and capacity in communicating with me. Their expression and/or enactment was after several encounters of developing relationship and during an extended episode of sitting together. For example over a meal, eventually some people expressed a pithy verbal statement or made extended commentary. Their statements displayed their apt reflection on their situation and their honesty and insight. The person appeared to become responsive to my attentive and attuned listening and eye contact, my awareness and “matching” their emotions in the moment (Pembroke 2019, p. 140). Previously, in the research literature I have not found this ability recognised in people with advanced dementia. In a parallel one-to-one situation of diagnostic interviews Katz and Shotter (1996)[6] have identified the ability of their patients to make profound statements regarding what is important and meaningful to them concerning their lived experience. In their research Katz and Shotter (1996) suggest the significance of these moments:

> *It is in our capacity to respond to these fleeting moments in extraordinary, rather than ordinary, routine ways that enables us to create a novel form of living contact with the [person]. For it is in those living moments of talk that we can find the patient, their 'world', and what it is like for them, trying in the face of their illness, to live in it (p. 921).*

Through such careful listening, Katz and Shotter have been able to hear people’s deeper meanings and concerns. This approach to their praxis has assisted these practitioners in their understanding of the significant aspects of the “patient’s” lived experience. They have learnt how these aspects affect the person’s daily life, and responses to certain situations. According to Katz

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[6] When this article was written, Katz was a social scientist and Shotter was Emeritus Professor of Communication, both at Harvard Medical School. Shotter has written on the subject of communication between health professionals and with patients, particularly on developing creative ways of interacting and relationships to facilitate holistic assessment, diagnosis and healing care.

and Shotter it is when we “pay attention” (Mary Oliver, The Summer Day)[7] to these moments that we engage not just with a professional gaze and cognitive awareness. Rather we connect deeply with the person within the context of attentive, attuned and affected relationship with them. Then we may hear or observe the person making a pithy yet profound and meaningful statement concerning their lived experience that seems to be the essence of what matters to them. Katz and Shotter (1996) remind us that we may overlook or forget the value of these “fleeting moments” when the person makes what seems like a brief statement or gesture. This occurrence indicates the importance of the dialogical and relational aspects in interactions as the person expresses and/or enacts their voice with another. In their words or gestures the person affects, teaches and/or informs the listener regarding matters personally significant to the person in their lived experience. The person’s statement or gesture may indeed become “the extraordinary in the ordinary”, revealing something fresh and fascinating and even poetic about their lived experience (Katz & Shotter 1996, p. 929). Moreover, in remaining attentive the listener might become aware of other moments that are significant but previously were not noticed. I have now embedded this understanding and praxis of Katz and Shotter into my own chaplaincy praxis. These “fleeting moments” of the person’s expression have become the source of much self-reflexivity and theological reflection in this study.

To demonstrate this process of self-reflexivity and theological reflection in my research experience, I describe the encounter when the person gives some pithy and profound comment, from my reflective journal:

> *In paying attention I hear this person’s words and observe their gestures within myself, moving inside and affecting me. In this moment I stand at the door, then sit within their lived experience briefly, and glimpse their world from their perspective, within them. In their brief utterances or gestures the person voices what matters to them, how they are affected and how they respond to others and their situation. I learn something of what it is like for this person. In privileging and recognising this person’s pithy and profound words and gestures I begin to hear and understand what moves and affects them, and the significance they place on this moment. Perhaps this person is even expressing or enacting what this moment of being together, interacting and being in relationship means to them. Moreover, in this moment the person may indeed be uttering what for them is the ultimate meaning of life, and their last testament. In this enactment of their voice this person displays*

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[7] Mary Oliver (1935-2019) won a Pulitzer Prize for her poetry. Her anthology includes “The Summer Day”. She published several poetry collections, including *Dog Songs: Poems* (Penguin Books, 2015). Her poems are often read as therapy by people experiencing mental health issues.

> *their enthusiasm, appreciation and enlivenment. This moment becomes an invitation into what this person's world is like for them in this context, what and who helps or hinders them, and what is most important to them. My praxis has been enhanced by this learning. Through listening to and observing people during the course of my fieldwork and now in my pastoral encounters, I have learnt not to miss these moments but to pay attention to the person (RJ, Book 2, 31/08/2018).*

Katz and Shotter (1996) remind us that we may overlook or forget the value of these "fleeting moments", such as when the person makes what seems like a brief statement or gesture, which they describe as moments of "boundary crossing":

> *navigating worlds of difference; making room for another person, a different point of view or stance; opening up a new space between [the person and the other … between the larger cultural context, or within the local culture created moment by moment by what is at stake for each participant (p. 920).*

Throughout the extracts in Chapters 6 to 8 there are examples of the person voicing pithy profound statements with their capability and capacity. At times in the course of my fieldwork, in playing back the audio tape I have been impacted by the person's profound words that I had overlooked during our encounter. The person's words have challenged me to reconsider my responses, or lack thereof. Self-reflexively and theologically, I have learnt again the necessity of not overriding the person's speaking to others. Instead by remaining attentive and attuned to the person for a lengthy period, I value their participation and contribution. However, in this I am reminded of Lifestyle Assistant, Bonnie's comments (see Extract 8.4) about needing to be self-aware and prepared so that we are attentive and attuned when we are with the person to receive from them. Then we may be and do what we can. Self-awareness assists the staff member to be inclusively engaged and supportive of the person and their voice. In this the staff member may become aware of the person's deeper expression of themselves and their meaning in their life, as well as their own meaning and purpose.

The aptness and profundity with which the person expresses their voice at times, both verbally and non-verbally, indicates that something more may be happening within the person. They may be assimilating and reflecting on their current interactive experience with another person as it happens. The person's expressions and/or enactments exemplify that episodes of interaction between people are "inter-bodied", "dynamic" and meaning-making, only possible when people participate together in relationship to make them happen (Zeiler 2014). This additional discovery makes a significant contribution to knowledge in again confirming the person's ability to be aware and respond astutely to their situation and those around them. This finding contradicts presumptions that a person with advanced dementia is mute and unable to meaningfully communicate verbally, and is unable to respond and reciprocate in relationships. This finding also reinforces the necessity for the person to be recognised, respected and responded to in their daily life. In paying attention to what matters to the person, “the old problems become irrelevant” and we may learn new perspectives and praxis (Shotter 1998, p. 78).

This study thus resonates with previous studies that affirm reciprocal, interdependent relationships as efficacious, and promoting the spiritual dimension and well-being of people (Carr, Hicks-Moore & Montgomery 2011; Hudson 2012; Perkins et al. 2015). These interactions become meaningful moments (Hillier & Stokes 2012), and may become epiphanies for each person who participates (Zubrick 2016). In her doctoral studies MacKinlay (1998, p. 36) defined the spirituality of the older person as “‘that which lies at the core of each person’s being, an essential dimension which brings meaning to life”. MacKinlay (2006) later interviewed people in the fourth age of life, and reiterated her earlier definition as a result of her research. However, MacKinlay’s subsequent research did not include people with advanced dementia. In focusing on the central participation of people with advanced dementia this study has found that they are able to express in their utterances and enact in their gestures their responses to who and what remains important, and even ultimately important, in this phase of their life.

Attentive and attuned care includes supporting each person to express and enact their voice and enhance their relationships with others. We now consider how the findings relate to policy and praxis development in residential aged care organisations and their staff.

9.6 Relating the Findings to Policy and Praxis Development

This final section describes the importance of aged care organisations and their staff being committed to promoting the person’s voice. Arguably, as evidenced in this study, the organisations and staff who provide care have specific accountabilities and responsibilities to the person. They are legally and morally obligated to uphold the rights and needs of all residents to experience homes where safety and quality care are paramount. Paying attention to people with advanced dementia and their voices, and gaining an understanding of their lived experiences, have the potential to transform the perspectives and attitudes of others towards the person. Praxis as intentional practices by staff may then be informed and motivated by personhood values and principles and relational ways of being and doing with the person.

In Chapter 4 when explaining my methodology, I described my bricolage approach to this study. By piecing together eclectic strategies and notions the bricoleur is considered to traverse “liminal frontiers”, where “formal knowledge” is recombined with “boundary knowledge”, in order to offer transformed understandings and “consciousness” (Lincoln 2001, p. 694). In this thesis through the exploration of the little-researched voice of the person with advanced dementia in their intra-personal and interpersonal contexts, this bricolage has assumed a critical-political research agenda. I have sought to discover new knowledge that may transform praxis for trans-disciplinary service providers (Rayner & Warne 2016; Yardley 2019). This approach is critical in the aged care sector. As identified in this thesis in Australia this sector is in the midst of addressing the current and monumental recommendations handed down by the Australian Government Department of Health and Aged Care and the Aged Care Quality and Safety Commission. These reforms are in response to the Royal Commission into Aged Care Quality and Safety, consultation with stakeholders in the wider community, and particularly consumer feedback. The Royal Commission Final Report discerned overwhelming support from respondents that the aged care sector must work towards a transformed culture throughout that encourages excellent praxis. The report identified that this praxis is truly consumer-centred, and no longer primarily a medical and task-oriented model, but supportive of people's social and emotional needs (Royal Commission into Aged Care Quality and Safety 2021c, p. 76). Commissioner Briggs challenged all misplaced perceptions of people with advanced dementia with her pertinent comment:

> *Old age is a part of the lifespan that can hold as much promise and meaning as all other stages of life. Later life should be appreciated as a time for living, not biding time. This will help move the concept of aged care towards something more fulfilling and empowering for older people…if a lesson is to be learnt, it is that resident-centred care means everyone's voice must be heard and respected regardless of being verbal, nonverbal, advocated, evidenced or witnessed…they must be given an opportunity to be heard and they must be listened to…(Royal Commission into Aged Care Quality and Safety 2021b, pp. 32-3)*.

I concur with her definitive statement and its objective. This thesis is being written when aged care is at the crossroads between confrontation and crisis, with the hope that there will be a radical transformation of the aged care sector in its ethos, policies and practices into praxis as positively intentional practices. The recognition of the voice of the person is crucially important. It is a political and personal issue for so many in wider society.

The question is *not:* How will the transformed context take account of the voice of each person? *Rather the question must be:* How will the voice of the person and their lived experience be heard in relationships in order to transform residential aged care?

I will refer to just two critical aspects of the aged care organisation as they relate to facilitating and promoting the voice of the person with advanced dementia: voice as a feature of organisation's ethos, and voice in staff formation.

Voice in the organisation's ethos

This thesis resonates with the Royal Commission Final Report that the care of each person living in residential aged care is premised on valuing and respecting them. This means acknowledging and responding to every person's voice as enacting their inner and outer lived experiences (Royal Commission into Aged Care Quality and Safety 2021b, p. 33). This is not a straightforward goal to realise. Rather this occurs through intentionally developing the purposes and praxis of the care environment at every level of the organisation.

This study aligns with three recent studies (de la Perrelle et al. 2022; Haunch, Downs & Oyebode 2022; Slape 2019) which each highlighted that the organisation's commitment is crucial at every level to recognising the personhood of every person involved. This ethos includes every resident, every staff member, every family member, and every manager and executive connected with the organisation. Every person matters. Such a culture is scaffolded on all organisational leadership, management and staff being committed to such values, and being accountable to one another to uphold them. When the organisation's formal leadership exemplify and inculcate the organisation's ethos as interactional and relational, this permeates through the management and leadership team's approach to care, down to all staff (de la Perrelle et al. 2022; Hudson 2012). When interactional and relational praxis is routine, then developing relationships of respect and recognition are the motivating force and stimulus for engaging with each person and responding to their voice. Therein staff members also find their caring work personally meaningful. When staff enact principles of courtesy, respect, warmth and friendliness, genuine appreciation and relationship, there seems a deeper connection, reciprocity and pleasure for all involved. There is an ongoing reinforcement of mutual recognition and affirmation in this interdependent community. This ethos recognises and affirms the personhood and well-being of each person and their quality of life. Hudson (2012) asserts:

> *With interdependent relationships at the core, a community spirit enlivens, emboldens and transforms residential aged care (p. 66).*

The recommendations of the Australian Royal Commission for the aged care sector are based on a rights-based holistic model of care that redresses negative practices. Transformative praxis first and foremost recognises, respects and responds to the needs, choices, preferences and requirements of older people within the context of engaging in interaction and relationships (Royal Commission into Aged Care Quality and Safety 2021c, pp. 32-3, 218 Recommendation 13). This approach to care has the transformative power to shape the whole organisation and each staff member to become the person they need to be. The formation of staff enhances their ability to care for every person respectfully and responsively within this context.

Voice in staff formation and training

The initial reforms after the final report of the Australian Royal Commission into Aged Care Quality and Safety have for the most part, focused on just pay and conditions for the aged care work force. Arguably the best resource of the organisation is its staff. The Royal Commission makes a range of recommendations regarding the formation and development of the aged care sector's workforce. As a whole the aged care sector has been deficit in its provision of educational opportunities for its staff, especially in "age-related conditions and the complexities of associated health and personal care requirements", palliative care and dementia (Royal Commission into Aged Care Quality and Safety 2021c, p. 41). Sustaining and strengthening staff in their daily work requires training, ongoing formation and mentoring, and in times of increased emotional labour, debriefing and counselling available as needed (de la Perrelle et al. 2022). These provisions demonstrate to staff that they and their skills are valued and considered worthy of investment, development and retention. Staff require training in the specifics of specialised care and mentoring, by experienced staff with expertise in caring for, and relating with, people with advanced dementia. Such training facilitates all staff to be confident in their roles and engage comfortably and relationally with residents during personal care. Thus each staff member participates in generating a positive culture of care. Organisational culture that recognises the personhood of its staff and cares for them, also enhances their praxis in upholding the personhood of each person and their voice (Slape 2019, p. 73).

The Royal Commission Final Report has recommended various necessary reforms to the training of staff providing direct personal or clinical care. These recommendations requiring staff development are commensurate with staff responsibilities in the intensity of caring for people with complex needs, and particularly caring for people with advanced dementia (Royal Commission into Aged Care Quality and Safety 2021c, pp. 261-2, Recommendations 79 & 80). Learning from staff with experience and expertise can happen in the performance of one's daily work. But staff stepping aside from the daily routine to focus on professional development enables the formation of values and skills, reflection and self-reflexivity which facilitate self-awareness, resilience and commitment. The development of these qualities supports personhood in all aspects of their care.

9.7 Conclusion

This current study, in applying an appreciative and strength-based approach, has found that the following elements or themes support, encourage and promote the person in the expression and enactment of their voice in the advanced stage of dementia. These are:

- the acknowledgement of the person's value, belonging and reciprocity in interdependent community;
- the recognition of the person's ongoing capabilities and capacities to voice and initiate, interact and form relationships according to their voice repertoire;
- the knowledge, encouragement and use of each person's voice repertoire by staff and family;
- the encouragement of interaction by staff in the various activities from personal care to recreation;

- the recognition and encouragement of the person’s continuing agency, identity and storied-life by others;
- the person’s continuing spiritual connections with who and what is important in their life and how the person chooses to enact these;
- the organisational ethos and leadership promoting voice through interaction and developing relationships;
- the training and ongoing formation of staff in values, personhood, communication and relationships.

In this study these “core elements” in supporting, encouraging and promoting the person’s voice resonate with the ways of acknowledging their personhood. These core elements occurred through respect, recognition, and responsiveness to people and their voices within the context of forming, developing and deepening relationships.

Of significant note are several findings of this study that occurred within the space of trustworthy, attentive and attuned relationship. The person with advanced dementia, when deemed unable, may express and/or enact the deeper aspects of their lived experience with their continuing capability and capacity by:

- taking initiative to extend being together with the other person;
- using verbal language in single words, phrases or sentences, and pithy comments;
- using verbal language to talk of their grief, loss and trauma;
- showing understanding of their family’s conversation and extending this with their apt comments and gestures.

Overall, this study with people with advanced dementia extends that of Hennelly and O’Shea (2022) in their findings of the “core elements” of personhood in dementia, including in long term care settings. Therefore I argue that there is a significant connection between the lived experience of the person in the continuing reality of their personhood and the enactment of their voice. In brief, personhood could be defined as the ontology, a fundamental understanding of the person’s ongoing presence and value in this community of the aged care home and in the world (Parker 2015). The person’s voice is the epistemology (Carter & Little 2010), how in particular practical ways they demonstrate, perform, and/or state those elements of their lived experience, and how others come to know who they are as a person. Where and when personhood and person and relationship-centred praxis have been evidenced in this study, the person has been prompted to enact their voice. Often they have done this spontaneously without inhibition, responsively according to their unique experience, and confidently as a person of worth.

Having undertaken this study to address the two research questions, and on the basis of my findings, I now extend the original definition of the person’s voice from Chapter 3 (p. 42).

My expanded definition of the voice of the person with advanced dementia is:

The voice of the person is an innate urge and meaningful manifestation of their person-hood, in their presence, consciousness and awareness of their lived experience. The person enacts their voice in some embodied form according to their intact voice repertoire of capabilities and capacities, and through exercising their personal characteristics of agency, identity and storied-life. Their voice provides insights into the lived experience of the person. Through their voice the person demonstrates their desire for interaction and relationship with others. As such the person's voice is situated, giving their voice personal, social and spiritual significance and meaning. Through the acknowledgement and responsiveness by others to their voice, the person's self-esteem, important connections, and well-being are enhanced, nurturing their being in their community/spiritual dimension.

The following chapter brings this thesis to its conclusion. Chapter 10 returns to and summarises my responses to each of the research objectives as my original contribution to knowledge. The chapter also recognises the limitations of the current study and suggests future possibilities for research alongside people with advanced dementia.

CHAPTER 10 CONCLUSION

Introduction

This thesis comes to the concluding chapter having evidenced and appreciated the voices of people with advanced dementia. Threaded through each chapter has been the realisation that each person declares their presence and participation in their context through their voice. In this way the person enacts their reactions and responses to their inner experiences and to their interactions with their circumstances and others in their world.

The form of this final chapter is as follows: 10.1 ‘Addressing the Research Objectives’ as Original Contribution to Knowledge; 10.2 ‘Undertaking Research with People with advanced dementia’, outlines methodological learnings from this research experience for future research and praxis; 10.3 ‘Limitations of Thesis’, considers some aspects not included in this thesis; 10.4 ‘Future Research’, recommends further possibilities for research in the light of this thesis, the Australian Royal Commission into Aged Care Quality and Safety, and ongoing relevant issues in the aged care sector; 10.5 ‘Conclusion’, returns to the final major points of this thesis in relation to the voice of the person with advanced dementia.

10.1 Addressing the Research Objectives

My original contribution to knowledge is expressed in the objectives of this thesis as:

- positioning people with advanced dementia as central participants and contributors;
- exploring their lived experiences in voicing themselves and the significance this has for them;
- examining how the facilitation of family and staff members in a wide range of roles promotes their voices;
- exploring how the person’s voice relates to their spiritual dimension and how spiritual care praxis may promote their voice.

I now summarise my original contribution in relation to each of these objectives.

10.1.1 People with advanced dementia as central participants and contributors

In making my original contribution to knowledge this thesis features people with advanced dementia as the central participants and key informants, and the significant diverse ways in which they continue to voice their lived experience. However, as described in Chapter 2, the social imaginary of the person may be of a person who is uncommunicative, bed-bound in silence or subjected to incomprehensible television or radio noise. In an environment starved of interaction and relationships, the person becomes silent and unresponsive, perpetuating their positioning as marginalised and excluded. What a difference for the person when they are positioned in the midst of an environment instilled with interactive opportunities and relational experiences. The person displays their urge to communicate, to reach out and relate with others using their unique voice repertoire. Some people use words - singly, in phrases and at times sentences, some sounds, and all with non-verbal language in facial and bodily gestures. The person reveals more of their voice repertoire when interactive occasions happen through their day as people encounter one another, staff and family members. The ways that the person enacts their repertoire, in taking initiative to communicate or respond, is an indication of their intact and embodied capacity and capability to express their consciousness of their inner experiences, and their awareness and responsiveness to their outward circumstances and those around them. This may not happen every day as the person's lucidity, capability and capacity may vary, but it will happen.

The variety of ways that a person may express their voice highlights the multi-faceted aspects of voice, in embodiment both verbally and non-verbally, and its diverse and nuanced enactments. There are a multitude of purposes and meanings for a person articulating their voice, their agency in their needs and choices, their feelings such as sadness and joy, their interaction with others, and their relationships with them. This emphasis is crucial given that through their agency, identity and storied-life, each person displays their consciousness, awareness and resolve to continue to be and become in their daily life. In so being they seek out experiences in which to find meaning and purpose, not to only exist but to be enlivened. Moreover, when we realise again that, apart from one person, each person in this study died within, or just after, the year in which the fieldwork took place, this period was their final opportunity to live and move, and have their being. As Luke proclaimed, "[M]ake the most of the day…that's all we want, I think. Isn't it?" Their enlivened being and their voice remain as a testimony to living till their end of life.

10.1.2 The significance to the person in voicing their lived experience

In this thesis my original contribution to knowledge has recognised that the person with advanced dementia has their own continuing voice, highlighting their unique presence and contribution in the world. This study, with an appreciative and strength-based approach, has reinforced that the person continues to seek out interactions and relationships with others and participate. The person endeavours to live out a meaningful life in the present moment. The person is truly aware when someone is desiring to interact and share relationship with them. There is no room for pretences since the person perceives another's interest and involvement with them, or disinterest in them. Positive relational experiences matter to the person and enliven them. When their day is devoid of such relational experiences this appears to have a cyclical impact, negatively affecting their mood, their demeanour, and their overall being, and diminishing their responsiveness.

When the person initiates an interchange with others or responds to another resident, or a staff or family member, the interaction encourages their capabilities, desire and capacity to voice themselves in the present. Such times are opportunities for the person becoming with others through making their contribution and responding, developing deeper relationships and sharing meaningful moments together. The person can share these moments with other people living in the home, or family and staff during their various activities. Accordingly, each person portrays that “narrative foreclosure” (Bohlmeijer et al. 2011) is not an option for them. Rather, the person is still engaging in new relationships, participating and becoming in the ongoing narrative of their storied-life. Moreover, the person finds meaning and purpose, an enlivening sense of worth and well-being in expressing themselves to others, contributing, and reciprocating with others. The importance of the person being agential and never losing their desire to offer themselves in their world, is the becoming of their presence and participation in their daily life. “This is me…” some articulate, while others enact this non-verbally. They also retain the ability to recognise the significance of the moment and its value to them personally, through their ongoing engagement and enthusiasm.

Such lived experiences can be built upon as relationships with one another develop and deepen over time, and people value their time spent together. Moreover, when someone stays and spends time with them the person may speak words responsively to this opportunity, use more extensive verbal language in repeating the words of the other person, and/or make further statements expressive of their reflective insights. As a listener-observer I have found these statements are often profound in their content. While being a gift to someone else, these moments are nevertheless the person revealing that this everyday occurrence of being together has profound significance and meaning to them personally. In so being, the person is able to express their self and their needs and continue to flourish in this phase of their life.

10.1.3 The facilitation of family and staff members in promoting the person’s voice

This thesis advocates for the inclusion, acknowledgement and attentiveness to the voices of people with advanced dementia regarding their value, ongoing personhood, interdependence and citizenship. The supportive presence, care and contributions of family and staff members in a wide range of roles, have demonstrated how these factors encourage the person and provide them with opportunities to express and enact their voice in their daily life within community. This understanding of the person provides the foundation for holistic residential aged care. Moreover, this understanding offers hope for transformative perspectives of care for people with advanced dementia in aged care organisation’s policy and provision of both residential and community services. Earlier, Kontos (2006) stated that the contribution of people with advanced dementia transforms positively our perspectives, understandings and attitudes towards them.

Now is the time to reimagine how people with advanced dementia are able to participate in various situations, including research, and are acknowledged for their insights into their care. Thereby, the person with advanced dementia has the opportunity to live as fulfilling a life as possible in relationships and interactions with others, with care attuned, accurate and appropriate to their needs, choices, opinions and concerns.

As has been shown in this study family members continue to have an important place in the person's life. Their positive contribution and interaction with the person enable and enhance the person's sense of self-worth, purpose and meaning. The person displays some awareness, acknowledgement and affirmation of family members' continuing presence with them. Moreover, through being together in familial intimacy and for longer periods, the person's awareness and well-being may generally heighten (Walmsley & McCormack 2017). However, grief and loss may be ongoing issues for family members and inhibit their involvement with their relative. The provision of support by staff members, including pastoral carers, may assist family to affirm the value of time spent together and the enduring significance of their relationship with the person. Family members have a unique place and part to play in the person's life. They continue to hold the person (Lindemann 2010) and encourage them to perform their storied-life, and advocate for and explain their storied-life to staff members.

When staff members perform their specific roles as facilitating the voice of the person, they enact values and attitudes of the respect and dignity of the person (Barnes et al. 2015, p. 12). As staff embrace an ethic of care, of attentiveness, competence, responsibility, trustworthiness and responsiveness, there is consistency in the ways they offer care. Every staff member in every role makes their contribution, investing themselves in the lived experience of the person by forming a relationship with them. In greeting and interacting with each one, in making time to listen to how their day is going and, if necessary, referring their needs to the appropriate staff member, staff show to each person that they are valuable, respected and matter. Thereby each person lives every day, not merely by existing but by endeavouring to participate and be "generative" (Doyle, Rubinstein & de Medeiros 2015), becoming enlivened as they express and enact their voice. Through connections in relationships and interactions the person co-creates meaning and human becoming with others. Thus they continue with others to affect and be affected, to receive and reciprocate, to transform and be transformed in their context. Such becoming experiences nurture each person to contribute to the pattern of communal interdependency.

10.1.4 The relationship of the person's voice to their spirituality

This study provides many examples of the ways in which the person's expression of their voice has connected them spiritually with who and what is important in their life. Connections with others may happen in a variety of ways. In one-to-one interaction with other residents and/or their family, each person expresses giving as well as receiving in mutual relationships and reminiscing (Vigliotti, Chinchilli & George 2019). Connections happen in diverse individual activities, such as sitting with another person in conversation or with an animal companion, going for walks in the garden and enjoying nature, connecting with self, with others, with God or a Higher Being, and religious rituals, or as transcendence. Connections also happen in group activities of singing and church services, music, craft and artistic activities wherein people's spirits are nurtured with a sense of pleasure and well-being, in interdependent community.

My original contribution to knowledge is that a person's participation may elicit their voice as they experience deep connection and well-being permeating their being. Their sense of becoming in well-being may last long after the activity has finished, and can be described as being "at-home" within oneself, with others, with God, or as self-transcendence (Simpson 2006). Relationships between each person and staff have recognised the person's voice in their agency, identity and storied-life and during interactions. The person is able to express in their words or gestures the emotional and spiritual significance to them personally of these relationships in sustaining their well-being and enlivening them in their daily life.

10.2 Undertaking Research with People with Advanced Dementia

My positioning in this research was broadly articulated as: respect for, attentiveness to, and reciprocity with each person according to their individuality; and in my attitudes and behaviours trustworthiness and accountability to the person and their interdependence with others. As a result of my relationships and interactions with each person I have become more aware of the important aspects of being alongside and engaging with them. At times I have learnt about the salient details later during my theological reflection and self-reflexivity, in the solitude of writing up field notes, or listening to recordings of interactions. I now discuss several methodological implications for acknowledging and involving people with advanced dementia as central participants, discovered or confirmed in the course of this research.

10.2.1 Premising all encounters with the person on developing relationship

Being conscious of who the person is, calling them by their name and acknowledging their person-hood promotes an ease between people and oneself. Informed by personal and chaplaincy experiences and by relevant literature, I knew that a person with advanced dementia responds positively to another when they are engaged and have a relationship with them (Sabat & Lee 2011). The notion of relationships in the research process was at first ambiguous to me. Ethnographic theory emphasises the balance between objective distancing and subjective immersion as a researcher. As a spiritual care practitioner accustomed to forming deep connections with people, I did not want to compromise my researcher role. Therefore, I initially sought objectivity above subjectivity and undervalued the significance of relationships. Being together regularly in developing relationship revealed how each person desired to voice more of themselves. This experience became a turning point, leading me to prioritise relationship with each person in the research context. Arguably, a person's participation occurs because they want to form and develop relationship with the other.

10.2.2 Being with the person and where they are at in the moment

The person's desire to participate is indicated by their responsiveness in a state of well-being. Empathising and providing a safe communicative place of attentive calm and support is vital. Being present, thoroughly attentive, adjusting to and moving with the person in the dynamic of the interaction assists the person to voice themselves. Using the person’s voice repertoire in mirroring their gestures, aligning oneself with their words, phrases or sounds (Davis & MacLagan 2014), and asking a question with a word or phrase and a raised inflection, indicates one is interested, understanding and following the person. The person’s voice verbally and/or non-verbally may modulate and their mood may change as they connect with positive or negative memories and emotions. Being with a person in their voicing is an opportunity for them to communicate and have deep connection with another and experience reassurance and well-being.

10.2.3 Valuing the person’s contribution and receiving from them

Often the person desires the opportunity to make their contribution to others with their continuing capability and capacity. A helpful way of conceiving of the person is to recognise that they are the host in their home and we are a guest (Nouwen 1975; Simpson 2006). Sharing in food and drink is an important cultural and/or religious event, enabling a person to voice their agency and identity by hosting and providing hospitality to another, as well as receiving from them (Richard 2000). Shared hospitality with another is a deeply meaningful and even sacred event, “in the recognition of [our] kinship, and the centrality of tacit and somatic ways of knowing” (Heshusius 1994, p. 20). Being a recipient of the person’s hospitality, creates connections between them and the other(s) in relationships of mutual understanding, equality, and even transformation.

10.2.4 Maintaining accountability to the person

Accountability to the person means being attentive and reflexive regarding one’s own feelings, attitudes and “embodied and inter-embodied” behaviours during every encounter and interchange (Watson 2019, p. 549). This includes paying attention to recognising within oneself and in others, expressions of power imbalances and the possible positioning of the person in demeaning ways in the midst of the demands, expectations and effects of daily work on self. One needs to be self-aware to not enact or align oneself with the taken for granted stereotypes and stigmatising behaviours towards the person, such as perceiving them as limited or dependent, or overlooking their presence and excluding their participation. Being accountable to the person means encouraging their confidence, capability and capacity to voice.

10.2.5 Assigning time to be present with the person

Being a non-anxious, unhurried presence with the person is essential as a mark of our recognition and respect for them. They pick up on our positive or negative demeanour. The person often appreciates the time together, finds meaning and is capable of voicing much more. Being aware and attentive to “slow” caring praxis (Lillekroken, Hauge & Slettebø 2017), means being present alongside the person to listen, observe and seek to understand. Such times create moments of meaningful togetherness, through the courtesies and rituals of greeting, interacting with, and leaving the person after each encounter in a place of well-being. The final leaving is also a special time to recognise each person and their contribution, say thanks, and goodbye. These methodological implications are consistent with acknowledging and affirming the significance of the personhood and voice of the person. They are relevant to the praxis of the researcher, staff member and spiritual care practitioner.

Reflexive development as a researcher scholar

With regard to my knowledge and skill development as a researcher scholar I have learnt to differentiate the often nuanced and divergent aspects of the roles of researcher and spiritual care practitioner. I understand the necessity of the ethical boundaries in being a researcher, as a caring outsider and to be absent from situations, as well as when to be appropriately present. This applied also to not overreaching into seeking consents or providing palliative care in the researcher role.

The reflexivity trail, establishing my rigour in this research, is one example of my growth as a researcher scholar. The values and skills of showing care and compassion, empathy and enriching one another's lives come to the fore in both being a practitioner and a researcher. I have found that it is possible to be reflexively both. Even though in writing that I recognise the paradox that my very presence and participation as a researcher means my maximum initiation and involvement. Equality may be considered often and only aspirational in the research relationship. Nevertheless, mindful reflexivity means I as the researcher have adhered to a moral commitment to divest myself of power and control and to facilitate the person's participation and contribution. In ensuring the reflexive audit trail is well sign-posted I hope that the reader has been able to travel well through the text and become engaged in the worlds of the participants. I have endeavoured to assist the reader to recognise the text as plausible and trustworthy (rigorous) and its findings as having applicability to both research and practitioner praxis (Koch & Harrington 1998, p. 889).

Where the roles of researcher and practitioner cross over in the care and nurture of people I have grown in learning again:

- not to underestimate the person's ability to speak for themselves, and to not overlook the person's presence and participation;
- to curb my enthusiasm and pace and allow the person time and opportunity;
- to recognise the desire of staff members to participate and share positive impacts of their work with pride and a sense of accomplishment;
- to appreciate the desire of family members to learn more about relating with their relative.
- I particularly have recognised that the person, when given attention and engaged in respectful relationship is still able to make profound verbal comments that have meaning and purpose and show profound reflection and insight.

This research has often been an intensely experienced and heartfelt endeavour for me. This way of being is genuinely the only way to be amongst people with advanced dementia. This is the cross-over between being a spiritual care practitioner and researcher scholar. This research has confirmed that people with advanced dementia truly recognise when the nature of the other person, that is the other's values and behaviours are genuinely respectful and, I believe, loving and kind with them. When the person senses that the other is genuinely appreciative and affirming, they have the space to be who they truly are and to voice themself.

10.3 Limitations of Thesis

This research was undertaken with an appreciative and strength-based approach as the means to understanding the lived experiences and perspectives of people with advanced dementia. Given its orientation this study may be deemed a biased account of these things. On the other hand, it is a real and detailed account representing their voices. As noted earlier, my intention was to provide as encouraging a place as possible to elicit the voices of people with advanced dementia. My approach was based on my personal and professional understandings of people with advanced dementia, and what encourages their participation according to the research literature (Cridland et al. 2016; Hosie et al. 2021).

The people in this study were firstly those who had consented to be in relationship and engage with me. Secondly, their participation was adjudicated by the informed consent of their substitute decision maker. Conversely this study does not represent the voices of those who did not wish to be in relationship or engage with me. But then again in refusing to engage with me they were expressing their voice in their agency. Their voices may have been expressed differently again with some form of contribution. Nor does this study represent the voices of those people with whom I had formed significant relationships, who moved into the palliative care phase before my gaining the informed consent of their substitute decision maker. From my practitioner experience I reflect that this phase of a person's life is of crucial significance for supporting a person's unique characteristics and their voice. However, I have not found the palliative care experience for the person with advanced dementia to be well researched regarding their psycho-social and spiritual needs and the communication of their voice.

This thesis, while considering a broad range of research from across the globe, is skewed towards the developed world and particularly the Australian context of residential aged care. As highlighted the Australian aged care sector is currently undergoing crisis and reformation. This national orientation may not prejudice the main context of the thesis topic. However, studies undertaken in other countries and ethnic communities in Australia and abroad would be warranted in discerning whether the findings of this study may apply to other contexts and cultures.

The sample in this study is a reasonable representation of the proportion of those residents of migrant and indigenous backgrounds to the overall number of residents in these particular aged care homes. The ratio in this study was 2:24, with the majority of residents being from Anglo-Saxon-European backgrounds, and the overall ratio in these homes was 3:80 in Home 1 and 7:118 in Home 2. However, this ratio is not representative of the proportions of people with advanced dementia from Indigenous and non-English speaking backgrounds in residential aged care in other geographical areas, or within ethnic-specific aged care homes. The inclusion of a larger sample of residents from migrant or Indigenous backgrounds would provide further insights. Such studies could include insights into providing care to people who revert to their original native language in the advanced dementia phase.

10.4 Future Research with People with Advanced Dementia

This study has provided a continuum of how the person may enact their voice across their day and how their voice may be facilitated. The outcomes of this research suggest several directions in which future research into the voice of the person with advanced dementia might proceed.

This research is based on the lived experience of a sample of people living in two particular residential care settings within the same organisation, which was an agency of a particular religious denomination. This organisation was separately incorporated and moderately well-funded and had highly satisfactory standards of care. Further research is needed where resources in psycho-social-spiritual care are limited and how to enhance people's continuing voices, capabilities and capacities, and well-being in those settings.

The Australian Royal Commission's recommendations for radical reform will prompt the development of an evidence-based staff training curriculum consistent with them. Research into effective training programmes focusing on the person's voice and their personhood will be required. Additional research could include appropriate staff training in assisting the person with specific issues such as their "responsive behaviours", grief and loss, and understanding voice repertoire.

Additional research is needed into how to assist family members to enhance their communication with their loved one with advanced dementia. An education program targeted to assisting family members with specific needs and concerns, such as those of younger family members, could promote changed perspectives, improve relationships and interactions between the person and their family and the well-being of all, in this significant phase of the person's life.

In this thesis the emphasis has been on the unique experience of each person living with advanced dementia. Dementia is a terminal illness with an uncertain life trajectory, with a projected timeline of five to ten years (UK Alzheimer's Society 2023). People with advanced dementia may live for a few months to many years (van der Steen et al. 2017). Therefore the care of people with advanced dementia needs a palliative care approach, in knowing the person deeply in relationship in every aspect of their personhood. This thesis has presented and advocates for this approach to care. The focus has been on each person living with dignity, respect and opportunities to express their voice and live well, including during their palliative care. Apart from studies regarding the person's communication of pain or delirium, there have been few studies focusing on how the person with advanced dementia expresses and/or enacts their voice in their end stage. The person's lucidity and ability to voice during this end stage of life requires further exploration that could enhance their care (Luckett et al. 2019), and recognise their voice as their last testament.

This thesis advocates for the inclusion, acknowledgement and attentiveness to the voices of people with advanced dementia. It also evidences the strengths of people with advanced dementia. Disseminating such knowledge through presenting the lived experience of people with advanced dementia could improve the perceptions and understandings of their families, friends, and people in the wider community. The development of dramatic presentations of the lived experiences of people with advanced dementia has been used to great effect in changing the perspectives of people in the wider community and specifically workers involved in direct care roles (Kontos, P et al. 2020). I am interested in exploring an arts-based project for this substantial body of work with respect to people with advanced dementia. This thesis contains many detailed stories and interactions that would provide much material for sensitive theatre productions.

Pia Kontos, researcher with people with dementia for more than two decades, an educator and activist turned dramatist, writes of using theatrical performance to change societal perceptions:

> *…we forged alliances across the globe to form Reimagining Dementia: A Creative Coalition for Justice. We are committed to shifting the culture of dementia care from centralized control, safety, isolation, and punitive interventions to a culture of inclusion, creativity, justice, and respect. Drawing on the emancipatory power of the imagination with the arts (e.g., theatre, improvisation, music), and grounded in authentic partnerships with persons living with dementia, we aim to advance this culture shift through education, advocacy, and innovation at every level of society (Kontos, P et al. 2021, p. 1396).*

Changes in stereotypes and prejudiced attitudes often happen as people in the wider community are exposed to alternative and real scenarios of positive lived experiences. Such community education would help to debunk societal stereotypes and encourage diverse and individualised perceptions of the person living with advanced dementia. As Dexter Kruger, 11 years, announced as a result of his personal experience of being alongside older people, “You can learn a lot from old people if you just listen” (Compass, ABC Television, 5/09/2021).

10.5 Conclusion

This thesis has made an original contribution to knowledge by positioning people with advanced dementia as central participants and contributors. Hence, in listening to and observing their voices and lived experience they have become the teachers. People with advanced dementia have shown the significant diverse ways in which they continue to voice their lived experience. In expressing their own continuing voice, the person has highlighted their unique presence and contribution in the world. They seek out interactions and relationships with others to participate and contribute with intention, meaning and purpose. This thesis has demonstrated that when a person experiences affirmation and acknowledgement of their capabilities and capacities from staff and family, their voice is encouraged. Connections to who and what is important to the person engage their spiritual dimension and enhance the expression of their voice. In maintaining these connections the person continues to experience self-expression, well-being and quality of life. The recognition of the voice of the person and their lived experience is crucially important to know what and how to provide for each person's care, well-being and what is more, their flourishing in this phase of their life.

This thesis is important in recommending acknowledgement and attentiveness to the voices of people with advanced dementia. Such regard values their ongoing personhood, interdependence and citizenship. In highlighting a multi-disciplinary and relational approach to the holistic care of the person this thesis has relevance to various individuals, groups, organisations and all who have relationships with and provide care to people with advanced dementia. As the Royal Commission has identified, there is much ageism in society with older people in the fourth age being stereo-typed and stigmatised (Royal Commission into Aged Care Quality and Safety 2021a, p. 76). This study challenges such attitudes and calls for changed perspectives and positioning of others shown in transformed praxis. As this study has revealed, positive praxis is already taking place in many residential aged care settings, but renewed perspectives of the person with advanced dementia require transformation at every level. This encompasses government policy and programs through to how each person spends their daily life, and into community based educational programmes changing negative stereotypes and stigma.

As to the future, Commissioner Briggs of the Australian Royal Commission emphasises the saliency of the increasing proportion of the oldest people with increasing needs and potential to be in their own home with chronic conditions for longer periods, reliant on informal carers and community services. The effect could be people needing to eventually move into residential care with more complex needs, and a decrease in the number of those able to provide care (Royal Commission into Aged Care Quality and Safety 2021a, p. 24). Therefore, radical transformation through the reform agenda of recommendations of the final report of the Royal Commission has its impetus in the current times and into the future.

The words of pioneer Kitwood, written in 1995, resound with as much pointed relevance today as they originally had, to the need and potential for transformation in the present age:

> *The old culture is one of alienation and estrangement. Through it we are distanced from our fellow human beings, deprived of our insight, cut off from our own vitality. The old culture is one of domination, technique, evasion and buck passing. To enter the new culture is like coming home. We can now draw close to other human beings, accepting all that we genuinely share. We can recover confidence in our power to know, to discover, to give, to create, to love, And this homecoming is a cause for joy and celebration (Kitwood 2007, p. 313).*

From a person's entry into the outer world with their first cry and/or bodily movements, to the time when they make their last testament and take their final breath, there is something as essential as breathing to living each day, that life is enlivened. The person testifies to their ongoing capability, capacity, dexterity and urge to voice themselves. The words and body language of each person who has participated in this study have testified to their presence and desire to be acknowledged, accepted, appreciated, and affirmed. The voices of people with advanced dementia have witnessed that their life, lived within relationships of respect and responsiveness with family, other residents, friends and staff members, encourage people to express and/or enact their voices.

This study has determined that when the person lives in a relationally rich and interactionally stimulating environment, they continue to initiate and respond with their unique voice repertoire. The voice of the person is their continuing communication of their inner self, their experiences, choices, feelings, needs, reactions, and outer responses. Their voice is recognised when others are attentive to listen, observe, and come to know the person in relationship. Their narrative then becomes a counter-story of what living with advanced dementia for the person means and becomes, in an interactional and relational context. Their narrative voice has the power to reframe perspectives of their human experience where people live flourishing and meaningful lives.

As Naomi proclaimed:

All I wonder. God! I still, I still, I still, I still…

You're love. You're love…

Well, that's wha...wein this worl, worl, worl…

why we're in this worl, worl, worl!

REFERENCES

ABC Channel 2 7.30 Report 2016, *Secret camera captures nursing home attempted suffocation*, 25 July 2016, Adelaide, <https://www.abc.net.au/news/2016-07-25/secret-camera-captures-nursing-home-attempted-suffocation/7624770>.

ABC On-line News 2017, *Oakden nursing home: death of patient Robert Blythe to be investigated*, Adelaide 5th June 2017 <https://www.abc.net.au/news/2017-06-05/treatment-of-another-patient-at-oakden-set-to-be-investigated/8588104>.

Agar, M 2008, *The professional stranger : an informal introduction to ethnography*, Emerald Group Publishing Ltd West Yorkshire, England.

Aged Care Quality and Safety Commission 2020, *Quality Standards*, Quality Standards, Aged Care Quality and Safety Commission, viewed 20/03/2021, <https://www.agedcarequality.gov.au/consumers/standards/resources>.

—— 2021a, *Charter of Aged Care Rights* viewed 18/01/2023, <https://www.agedcarequality.gov.au/resource-library?query=Aged+care+rights>.

—— 2021b, *Guidelines and resources for providers to support the new Aged Care Quality Standards*, Aged Care Quality and Safety Commission, viewed 20/03/2021, <https://www.agedcarequality.gov.au/providers/standards>.

—— 2022a, *Behaviour support plans: a fact sheet for residential aged care providers*, Australian Government, viewed 1/09/2023, <https://www.agedcarequality.gov.au/sites/default/files/media/fact-sheet-behaviour-support-plans.pdf>.

—— 2022b, *Code of conduct*, viewed 18/01/2023, <https://www.agedcarequality.gov.au/resources/code-conduct-aged-care-introductory-video-providers-and-workers>.

—— 2022c, *Launch of the aged care quality standards public consultation -webinar presentation*, Australian Government Department of Health and Aged Care, viewed 7/01/2023, <https://www.health.gov.au/sites/default/files/documents/2022/10/launch-of-the-aged-care-quality-standards-public-consultation-webinar-presentation-slides.pdf>.

Aged Care Sector Committee 2020, *A Quality vision for aged care*, viewed 18/01/2023, <https://www.health.gov.au/resources/publications/a-quality-vision-for-aged-care>.

AIHW 2021a, *Dementia in Australia 2021: summary report. Cat. no. DEM 3*, AIHW, Canberra.

—— 2021b, *Dementia overview: statistics*, viewed 19/02/2022, <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/dementia/overview>.

—— 2021c, *People's care needs in aged care* viewed 13/02/2021, <AIHW Gen (gen-agedcaredata.gov.au)>.

—— 2022, *Prevalence of dementia: key statistics*, AIHW, viewed 20/08/2023, <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/population-health-impacts-of-dementia/prevalence-of-dementia>.

—— 2023, *National policy response to dementia*, Canberra, viewed 26/08/2023, <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/national-policy-response-to-dementia >.

Alcoff, L 1991, 'The problem of speaking for others', *Cultural Critique*, vol. 20, no. Winter 1991-1992, pp. 5-32.

Allison, T, Balbino, R & Covinsky, K 2019, 'Caring community and relationship centred care on an end-stage dementia special care unit', *Age and Ageing*, vol. 48, no. 5, pp. 727-34.

Alsawy, S, Tai, S, McEvoy, P & Mansell, W 2020, ''It's nice to think somebody's listening to me instead of saying "oh shut up"'. People with dementia reflect on what makes communication good and meaningful', *Journal of Psychiatric and Mental Health Nursing*, vol. 27, no. 2, pp. 151-61.

Alzheimer Scotland 2019, *Delivering fair dementia care for people with advanced dementia: The Fair Dementia Care Commission*, Alzheimer Scotland, Edinburgh.

Alzheimer's Disease International 2019, *World Alzheimer Report 2019: attitudes to dementia.*, Alzheimer's Disease International, London.

Andrews, E 2017, 'Institutionalising senile dementia in 19th-century Britain', *Sociology of Health & Illness*, vol. 39, no. 2, pp. 244–57.

Atchley, R 2003, 'The continuity of the spiritual self', in M Kimble & S McFadden (eds), *Ageing, spirituality and religion: a handbook*, Fortress Press, Minneapolis, vol. 2, pp. 134-44.

Atkinson, P, Coffey, A, Delamont, S, Lofland, J & Lofland, L 2001, 'Editorial Introduction', in P Atkinson, A Coffey, S Delamont, J Lofland & L Lofland (eds), *Handbook of ethnography*, Sage, London.

Australia Alzheimer's 2004, 'Research consent for cognitively impaired adults' recommendations for institutional review boards and investigators', *Alzheimer's Disease and Associated Disorders, Consensus Recommendations*, vol. 18, no. 3, pp. pp. 171-5.

Australian Department of Health 2018, *National palliative care strategy 2018*, Australian Department of Health, Canberra, Australia.

Australian Department of Health and Aged Care 2018, *National palliative care strategy 2018*, Australian Department of Health and Aged Care, viewed 20/03/2021, <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>.

Australian Health Services Research Institute 2019, *How Australian residential aged care staffing levels compare with international and national benchmarks, A research study commissioned by the Royal Commission into Aged Care Quality and Safety, Research Paper 1*, University of Wollongong.

Australian Psychological Society 2018, *Australian loneliness report: a survey exploring the loneliness levels of Australians and the impact on their health and wellbeing*, Australian Psychological Society, viewed 25/08/2023, <https://researchbank.swinburne.edu.au/file/c1d9cd16-ddbe-417f-bbc4-3d499e95bdec/1/2018-australian_loneliness_report.pdf>.

Baars, J & Phillipson, C 2013, 'Connecting meaning with social structure: theoretical foundations', in J Baars, J Dohmen, A Grenier & C Phillipson (eds), *Ageing, meaning and social structure: connecting critical and humanistic gerontology*, Policy Press, Bristol, pp. 11-30.

Backhouse, T, Kenkmann, A, Lane, K, Penhale, B, Poland, F & Killett, A 2016 'Older care-home residents as collaborators or advisors in research: a systematic review', *Age and Ageing*, vol. 45, pp. 337–45.

Bakhtin, M 1987, 'The problem of speech genres (translation VW McGee)', in C Emerson & M Holquist (eds), *Speech genres and other late essays*, University of Texas Press, Austin, Texas, pp. 60-102.

Barclay, P 2014, *Towards a future without dementia: panel discussion with Advocate Christine Bryden, Dr Zoe Terpening, Professor Henry Brodaty*, ABC Radio National.

Barnes, M & Brannelly, T 2008, 'Achiving care and social justice for people with dementia', *Nursing Ethics*, vol. 15, no. 3, pp. 384-95.

Barnes, M, Brannelly, T, Ward, L & Ward, N 2015, 'Introduction the critical significance of care', in M Barnes, T Brannelly, L Ward & N Ward (eds), *Ethics of care*, 1 edn, Bristol University Press, pp. 3-20.

Bartlett, R & O'Connor, D 2007, 'From personhood to citizenship: broadening the lens for dementia practice and research', *Journal of Aging Studies*, vol. 21, pp. 107–18.

Basting, A 2020, *How to meaningfully reconnect with those who have dementia*, https://www.bing.com/videos/search?q=TED+Talks+Dementia+Ann+Basting&&view=detail&mid=E30E1888C98A5C04569DE30E1888C98A5C04569D&&FORM=VRDGAR&ru=%2Fvideos%2Fsearch%3Fq%3DTED%2BTalks%2BDementia%2BAnn%2BBasting%26FORM%3DVDMHRS viewed 8/10/2021.

Batra, S, Sullivan, J, Williams, B & Geldmacher, D 2016, 'Qualitative assessment of self-identity in people with advanced dementia', *Dementia*, vol. 15, no. 5, pp. 1260–78.

Beerens, H, Zwakhalena, S, Verbeek, H, Tan, F, Frans, E, Jolani, S, Downs, M, de Boer, B, Ruwaard, D & Hamers, J 2018, 'The relation between mood, activity, and interaction in long-term dementia care', *Aging & Mental Health*, vol. 22, no. 1, pp. 26-32.

Behuniak, S 2011, 'The living dead? The construction of people with Alzheimer’s disease as zombies, ' *Aging and Society*, vol. 31, no. 1, pp. 70–92.

Berchtold, N & Cotman, C 1998, 'Evolution in the conceptualization of dementia and Alzheimer's disease: Greco-Roman period to the 1960s', *Neurobiology of Aging*, vol. 19, no. 3, pp. 173-89.

Berendonk, C & Caine, V 2016, 'Life story work with persons with dementia in nursing homes: a grounded theory study of the perspectives of care staff ', *Dementia*, vol. 0, no. 0, pp. 1-21.

Bertau, M-C 2007, 'On the notion of voice an exploration from a psycholinguistic perspective with developmental implications', *International Journal for Dialogical Science*, vol. 2, no. 1, pp. 133-61.

—— 2008, 'Voice: a pathway to consciousness as ‘social contact to oneself'', *Integrative Psychological and Behavioral Sciences*, vol. 42, pp. 92-113.

Birt, L, Poland, F, Csipke, E & Charlesworth, G 2017, 'Shifting dementia discourses from deficit to active citizenship', *Sociology of Health & Illness*, vol. 39, no. 2, pp. 199–211.

Blythe, S, Chang, E, Johnson, A & Griffiths, R 2009, 'The efficacy of nurse implemented non-pharmacological strategies for the symptom management of agitation in persons with advanced dementia living in residential aged care facilities: a systematic review', *JBI library of systematic reviews*, vol. 7, no. 22, pp. 975-1003.

Bohlmeijer, E, Westerhof , G, Randall, W, Tromp, T & Kenyon, G 2011, 'Narrative foreclosure in later life: preliminary considerations for a new sensitizing concept', *Journal of Aging Studies*, vol. 25, pp. 364–70.

Boss, P 2010, 'The trauma and complicated grief of ambiguous loss', *Pastoral Psychology*, vol. 59, no. 2, pp. 137-45.

—— 2016, 'The context and process of theory development: the story of ambiguous loss', *Journal of Family Theory & Review*, vol. 8, no. 3, pp. 269-86.

Bourbonnais, A & Duchame, F 2015, 'The social positioning of older people living with Alzheimer’s disease who scream in long-term care homes', *Dementia*, vol. 14, no. 6, pp. 751–68.

Boyle, G 2014, 'Recognising the agency of people with dementia', *Disability & Society*, vol. 29, no. 7, pp. 1130-44.

Brabazon, T 2018, *On not being strong*, Brabazon, Flinders University, Adelaide, SA, https://www.youtube.com/watch?v=ES7Obic2iSU.

Brannelly, T 2011, 'Sustaining citizenship: people with dementia and the phenomenon of social death', *Dementia*, vol. 18, no. 5, pp. 662-71.

—— 2016, 'Citizenship and people living with dementia: A case for the ethics of care', *Dementia*, vol. 15, no. 3, pp. 304–14.

Brannelly, T & Bartlett, R 2020, 'Using walking interviews to enhance research relations with people with dementia: methodological insights from an empirical study conducted in England', *Ethics and Social Welfare*, vol. 14, no. 4, pp. 432-42.

Brecher, D & West, T 2016, 'Under recognition and undertreatment of pain and behavioral symptoms in end-stage dementia', *American Journal of Hospice and Palliative Medicine®*, vol. 33, no. 3, pp. 276-80.

Brewer, J 2000, *Ethnography*, Open University Press, Buckingham.

Broady, T, Saich, F & Hinton, T 2018, 'Caring for a family member or friend with dementia at the end of life: a scoping review and implications for palliative care practice', *Palliative Medicine*, vol. 32, no. 3, pp. 643-56.

Bronk, K 2012, 'The exemplar methodology: an approach to studying the leading edge of development', *Springer Open Journal Psychology of Well-Being: Theory, Research and Practice*, vol. 2, no. 5.

Bronk, K, King, P & Matsuba, M 2013, 'An introduction to exemplar research: a definition, rationale, and conceptual issues', in M Matsuba, P King & K Bronk (eds), *Exemplar methods and research: strategies for investigation. New directions for child and adolescent development*, Wiley Periodicals, vol. 142, pp. 1-12.

Brooker, D 2008, 'Quality: the perspective of the person with dementia', in M Downs & B Bowers (eds), *Excellence in dementia care: Research into practice*, Open University Press, Bucks, pp. 476-91.

Brooker, D & Surr, C 2006, 'Dementia Care Mapping initial validation of DCM 8 in UK field trials', *International Journal of Geriatric Psychiatry*, vol. 21, pp. 1018–25.

Brown, M, Mitchell, B & Quinn, S 2020, 'Meaningful activity in advanced dementia', *Nursing Older People (2014+)*, vol. 32, no. 6, pp. 14-9.

Brown, M & Tolson, D 2020, 'Introduction to living with advanced dementia series', *Nursing Older People (2014+)*, vol. 32, no. 3, pp. 12-6.

Brun, C & Rapp, R 2001, 'Strengths-based case management: individuals' perspectives on strengths and the case manager relationship', *Social Work*, vol. 46, no. 3, pp. 278-88.

Bryden, C 2006, *Dancing with dementia*, Jessica Kingsley Publishers, London.

—— 2015, *Nothing about us without us*, Jessica Kingsley Publishers, London.

—— 2016, 'A spiritual journey into the I-Thou relationship: a personal reflection on living with dementia', *Journal of Religion, Spirituality & Aging*, vol. 28, no. 1-2, pp. 7-14.

—— 2018, *Will I still be me? Finding a continuing sense of self in the lived experience of dementia*, Jessica Kingsley Publishers, London.

Bryman, A 2012, 'Ethnography and participant observation', in A Bryman (ed.), *Social Research Methods, 4th edn*, Oxford University Press, Oxford, pp. 430-67.

—— 2016, *Social research methods 5th edn*, Oxford University Press, Oxford.

Buber, M 1957, 'Elements of the interhuman', *Psychiatry Res*, vol. 20, pp. 105–13.

—— 1966, *The way of response*, Shocken Books, New York.

Byrne, B 2002, *The hospitality of God: a reading of Luke's gospel*, St Paul's Publications, Strathfield, NSW.

Caddell, L & Clare, L 2009, 'The impact of dementia on self and identity: a systematic review', *Clinical Psychology Review*, vol. 30, pp. 113–26.

—— 2011, 'Studying the self in people with dementia: How might we proceed?', *Dementia*, vol. 12, no. 2, pp. 192–209.

Cahill, S 2018, *Dementia and human rights*, Policy Press, Bristol.

—— 2020, 'WHO's global action plan on the public health response to dementia: some challenges and opportunities', *Aging & Mental Health*, vol. 24, no. 2, pp. 197-9.

Cahill, S & Diaz-Ponce, A 2011, ''I hate having nobody here. I'd like to know where they all are': can qualitative research detect differences in quality of life among nursing home residents with different levels of cognitive impairment?', *Aging and Mental Health*, vol. 15, no. 5, pp. 562-72.

Camacho-Montaño, L, Pérez-Corrales, J, Pérez-de-Heredia-Torres, M, Martin-Pérez, A, Güeita-Rodríguez, J, Velarde-García, J & Palacios-Ceña, D 2021, 'Spiritual care in advanced dementia from the perspective of health providers: a qualitative systematic review', *Occup Ther Int*, vol. 2021, p. 9998480.

Cameron, N, Fetherstonhaugh, D, Bauer, M & Tarzia, L 2020, 'How do care staff in residential aged care facilities conceptualise their non-verbal interactions with residents with dementia and what relevance has this for how residents' preferences and capacity for decision-making are understood?', *Dementia*, vol. 19, no. 5, pp. 1364–80.

—— 2021, 'How residential care staff conceptualize the identities of residents with dementia and its relevance for decision making', *Journal of Applied Gerontology*, vol. 40, no. 11, pp. 1551–8.

Campo, M & Chaudhury, H 2011, 'Informal social interaction among residents with dementia in special care units: exploring the role of the physical and social', *Dementia*, vol. 11, no. 3, pp. 401-23.

Canning, S, Gaetz, M & Blakeborough, D 2020, 'It takes time: building relationships and understanding through an intergenerational ballet programme', *Dementia*, vol. 19, no. 2, pp. 270–84.

Capstick, A 2017, *Reframing challenging behaviour as cultural resistance: the refusal of bare life in long-term dementia care*, 28/04/2017, <http://hdl.handle.net/10454/12121>.

Carr, T, Hicks-Moore, S & Montgomery, P 2011, 'What's so big about the 'little things': a phenomenological inquiry into the meaning of spiritual care in dementia', *Dementia*, vol. 10, no. 3, pp. 399–414.

Carroll, K 2009, 'Outsider, insider, alongsider: examining reflexivity in hospital-based video research', *International Journal of Multiple Research Approaches*, vol. 3, pp. 246–63.

Carter, S & Little, M 2010, 'Justifying knowledge, justifying method, taking action: epistemologies, methodologies and methods in qualitative research', *Qualitative Health Research*, vol. 17, pp. 1316-28.

CASP-UK 2018, *The qualitative checklist*, https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist.pdf, viewed 13/8/2018.

Castoriadis, C 1987, *The imaginary institution of society*, Polity Press, Cambridge.

Chase, S 2018, 'Narrative inquiry: Toward theoretical and methodological maturity', in N Denzin & Y Lincoln (eds), *The Sage Handbook of Qualitative Research 5th edn*, Sage Publications Inc., Thousand Oaks, pp. 546-60.

Chaudhury, H, Hung, L, Rust, T & Wu, S 2017, 'Do physical environmental changes make a difference? Supporting person-centered care at mealtimes in nursing homes', *Dementia*, vol. 16, no. 7, pp. 878-96.

Chenail, R 2011, 'Learning to appraise the quality of qualitative research articles: a contextualized learning object for constructing knowledge', *The Qualitative Report*, vol. 16, no. 1, pp. 236-48.

Chopp, R 1992, *The power to speak: feminism, language, God*, Crossroad, New York.

Chriqui, E, Kergoat, M-J, Champoux, N, Leclerc, B-S & Kergoat, H 2013, 'Visual Acuity in Institutionalized Seniors With Moderate to Severe Dementia', *Journal of the American Medical Directors Association*, vol. 14, no. 4, pp. 275-9.

Clare, A, Camic, P, Crutch, S, West, J, Harding, E & Brotherhood, E 2020, 'Using music to develop a multisensory communicative environment for people with late-stage dementia', *The Gerontologist*, vol. 60, no. 6, pp. 1115-25.

Clare, L 2010, 'Awareness in people with severe dementia: review and integration', *Aging & Mental Health*, vol. 14, no. 1, pp. 20-32.

Clare, L, Rowlands, J, Bruce, E, Surr, C & Downs, M 2008a, ''I don't do like I used to do': a grounded theory approach to conceptualising awareness in people with moderate to severe dementia living in long-term care', *Social Science & Medicine*, vol. 66, no. 11, pp. 2366-77.

Clare, L, Whitaker, R, Woods, R, Quinn, C, Jelley, H, Hoare, Z, Woods, J, Downs, M & Wilson, B 2013, 'AwareCare: a pilot randomized controlled trial of an awareness-based staff training intervention to improve quality of life for residents with severe dementia in long-term care settings', *International Psychogeriatrics*, vol. 25, no. 1, pp. 128-39.

Coffey, A 1999, *The ethnographic self: fieldwork and the representation of identity*, Sage Publns, London.

—— 2011, 'The ethnographic self', in *Sage Research Methods*, SAGE Publications Ltd, London.

—— 2018, 'In the field: observation, conversation and documentation', in *Doing ethnography*, SAGE Publications Ltd, Online pub date: February 08, 2021.

Cohen-Mansfield, J, Dakheel-Ali, M, Marx, M, Thein, K & Regier, N 2015, 'Which unmet needs contribute to behavior problems in persons with advanced dementia?', *Psychiatry Res*, vol. 228, no. 1, pp. 59-64.

Collier, A 2013, 'Deleuzians of patient safety: A video reflexive ethnography of end-of-life care', PhD thesis, University of Technology, Sydney.

Commonwealth of Australia as represented by the Department of Health May, 2021, *Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety*, https://www.health.gov.au/sites/default/files/documents/2021/05/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety.pdf.

Cortazzi, M 2001, 'Narrative analysis in ethnography', in P Atkinson, A Coffey, S Delamont, J Lofland & L Lofland (eds), *Handbook of ethnography*, Sage, London, pp. 384-94.

Cousins, S 2020, 'Experts criticise Australia's aged care failings over COVID-19', *The Lancet*, vol. 396, no. 10259, pp. 1322-3.

Cridland, E, Phillipson, L, Brennan-Horley, C & Swaffer, K 2016, 'Reflections and recommendations for conducting in-depth interviews with people with dementia', *Qualitative Health Research*, vol. 26, no. 13, pp. 1774-86.

Crotty, M 1998, *The foundations of social research: meaning and perspective in the research process*, Allen & Unwin, St Leonards, NSW.

Cupit, C, Mackintosh, N & Armstrong, N 2018, 'Using ethnography to study improving healthcare: reflections on the ‘ethnographic’ label', *British Medical Journal Quality & Safety*, vol. 27, pp. 258–60.

Curelaru, A, Marzolf, S, Provost, J & Zeon, H 2021, 'Social isolation in dementia: the effects of COVID-19', *The Journal for Nurse Practitioners*, vol. 17, no. 8, pp. 950-3.

Czarniawska, B 2004, *Narratives in social science research*, Sage Publications Ltd, London.

—— 2007, *Shadowing and other techniques for doing field work in modern societies*, Copenhagen Business School Press, Malmo, Sweden

Dadich, A, Hodgins, M & Collier, A 2016, 'Video reflexive ethnography: a creative approach to understand and promote brilliant organizational experiences ', in *ACSPRI Social Science Methodology Conference, 2016*, Sydney, Australia, pp. 60-70.

Dassa, A & Amir, D 2014, 'The role of singing familiar songs in encouraging conversation among people with middle to late stage alzheimer’s disease', *Journal of Music Therapy*, vol. 51, no. 2, pp. 131-53.

Davis, B & MacLagan, M 2014, 'Talking with Maureen: extenders and formulaic language in small stories and canonical narratives', in R Schrauf & N Muller (eds), *Dialogue and dementia: cognitive and communicative resources for engagement*, Psychology Press, New York.

de la Perrelle, L, Klinge, N, Windsor, T, Low, L-F, Laver, K & Cations, M 2022, 'Characterising trauma-informed aged care: an appreciative inquiry approach', *International Journal of Geriatric Psychiatry*, vol. 37, no. 9, pp. 1-10.

de Medeiros, K 2019, 'Confronting ageism: perspectives from age studies and the social sciences', *The Gerontologist*, vol. 59, no. 4, pp. 799-800.

de Medeiros, K, Saunders, P, Doyle, P, Mosby, A & Van Haitsma, K 2011, 'Friendships among people with dementia in long-term care', *Dementia*, vol. 11, no. 3, pp. 363–81.

de Witt Jansen, B, Brazil, K, Passmore, P, Buchanan, H, Maxwell, D, McIlfatrick, S, Morgan, S, Watson, M & Parsons, C 2017, 'Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study', *Journal of Clinical Nursing*, vol. 26, no. 9/10, pp. 1234-44.

Delamont, S 2004, 'Ethnography and participant observation', in C Seale, G Gobo, J Gubrium & D Silverman (eds), *Qualitative Research Practice*, Sage, London, pp. 217-9.

—— 2011, 'Ethnography and participant observation', in C Seale, G Gobo, J Gubrium & D Silverman (eds), *Qualitative Research Practice*, SAGE Publications Ltd, London, pp. 205-17.

Dementia Australia 2020, *Types of dementia*, Dementia Australia, viewed 13/02/2021, <https://www.dementia.org.au/information/about-dementia/types-of-dementia>.

Denzin, N & Lincoln, Y 2018, 'Introduction: the discipline and practice of qualitative research', in N Denzin & Y Lincoln (eds), *The Sage Handbook of Qualitative Research, 5th edn*, SAGE Publications, Inc., Thousand Oaks, pp. 1-26.

Department of Health and Aged Care 2021, *About the Dementia and Aged Care Services (DACS) Fund* Australian government, viewed 13/02/2021, <https://www.health.gov.au/initiatives-and-programs/dementia-and-aged-care-services-dacs-fund/about-the-dementia-and-aged-care-services-dacs-fund>.

—— 2022, *Serious Incident Report Scheme (SIRS)*, viewed 27/01/2023, <https://www.health.gov.au/our-work/serious-incident-response-scheme-sirs >.

—— 2023, *Revised Aged Care Quality Standards (draft for pilot)*, Department of Health and Aged Care,, viewed 15/08/2023, <https://www.health.gov.au/sites/default/files/2023-05/strengthened-aged-care-quality-standards-pilot-program.pdf >.

Dewing, J 2002, 'From ritual to relationship: a person-centred approach to consent in qualitative research with people who have dementia', *Dementia*, vol. 1, no. 2, pp. 157-71.

—— 2007, 'Participatory research: a method for process consent with persons who have dementia', *Dementia*, vol. 6, no. 1, pp. 11-25.

Douglas, J, Jung, S, Noh, H, Ellis, A & Ferguson, C 2021, '"If they don't like you, they are not going to eat for you": individual and interpersonal factors affecting certified nursing assistants' ability to provide mealtime assistance to residents with dementia', *The Gerontologist*, vol. 61, no. 4, pp. 552-62.

Downs, M 2011, 'End of life care for people with dementia: priorities for research and service development', in M Gott & C Ingleton (eds), *Living with ageing and dying: palliative and end of life care for older people*, Oxford University Press, Oxford.

Downs, M & Collins, L 2015, 'Person-centred communication in dementia care', *Nursing Standard*, vol. 11, pp. 37-41.

Doyle, P, Rubinstein, R & de Medeiros, K 2015, 'Generative acts of people with dementia in a long-term care setting', *Dementia*, vol. 14, no. 4, pp. 409–17.

Duckett, S 2020, *Australia's aged care industry needs to be rebuilt from the ground up not-renovate*, Canberra Times, viewed 23/08/2023, <https://www.canberratimes.com.au/story/7063604/we-need-to-rebuild-aged-care-in-australia>.

Eagar, K, Westera, A, Snoek, M, Kobel, C, Loggie, C & Gordon, R 2019, *How Australian residential aged care staffing levels compare with international and national benchmarks*, Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

Eggers, T, Ekman, S & Norberg, A 2013, 'Nursing staff's understanding expressions of people with advanced dementia disease', *Research and Theory for Nursing Practice*, vol. 27, no. 1, pp. 19-34.

Eiesland, N 1994, *The disabled God: toward a liberatory theology of disability*, Abingdon Press, Nashville, TN.

Eisenmann, Y, Schmidt, H, Voltz, R & Perrar, K 2016, 'Expression and perception of needs in severe dementia', *Journal of Hospice & Palliative Nursing*, vol. 18, no. 3, pp. 268-72.

Elliott, G 2011, *Montessori methods for dementia: focusing on the person and the prepared environment*, Franklin Press, Moonah, Tasmania.

Ellis, M & Astell, A 2004, 'The urge to communicate in severe dementia', *Brain and Language*, vol. 91, pp. 51-2.

—— 2011, 'Adaptive interaction: a new approach to communication', *Journal of Dementia Care*, vol. 19, no. 3, pp. 24-6.

—— 2017, 'Communicating with people living with dementia who are nonverbal: the creation of Adaptive Interaction', *PLoS One*, vol. 12, no. 8.

—— 2018, *Adaptive interaction and dementia*, Jessica Kingsley Publishers, London.

Erickson, F 2018, 'A History of qualitative inquiry in social and educational research', in N Denzin & Y Lincoln (eds), *The Sage Handbook of Qualitative Research, 5th edn*, SAGE Publications, Inc., Thousand Oaks, pp. 36-65.

Ericsson, I, Kjellstrom, S & Hellstrom, I 2011, 'Creating relationships with persons with moderate to severe dementia', *Dementia*, vol. 12, no. 1, pp. 63–79.

Evans-Lacko, S, Bhatt, J, Comas-Herrera, A, D’Amico, F, Farina, N, Gaber, S, Knapp, M, Salcher-Konrad, M, Stevens, M & Wilson, E 2019, *Attitudes to dementia survey results*, World Alzheimer's Organisation, London.

Fels, D & Astell, A 2011, 'Storytelling as a model of conversation for people with dementia and caregivers', *American Journal of Alzheimer’s Disease & Other Dementias*, vol. 26, no. 7, pp. 535-41.

Fetherstonhaugh, D, Tarzia, L, Bauer, M, Nay, R & Beattie, E 2016, '"The red dress or the blue?” How do staff perceive that they support decision making for people with dementia living in residential aged care facilities?', *Journal of Applied Gerontology*, vol. 35, no. 2, pp. 209-26.

Fetterman, D 2010, *Ethnography. Step by step 3rd edn*, Sage, Thousand Oaks, CA.

Finlay, L 2002, '“Outing” the researcher: the provenance, process, and practice of reflexivity ', *Qualitative Health Research*, vol. 12, no. 4, pp. 531-45.

—— 2006, 'Mapping methodology', in L Finlay & C Ballinger (eds), *Qualitative research for allied health professionals : challenging choices*, John Wiley, Chichester.

Fleming, R, Zeisel, J & Bennett, K 2020, *World Alzheimer Report 2020: Design dignity dementia: dementia-related design and the built environment* Alzheimer’s Disease International, London, England.

Fletcher, J & Meaningful Ageing Australia 2018, *ConnecTo: a tool for spiritual screening, Adapted by Meaningful Australia*, Meaningful Ageing Australia, Victoria.

Foley, S, Pantidi, N & McCarthy, J 2019, 'Care and design: an ethnography of mutual recognition in the context of advanced dementia', in *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*, Association for Computing Machinery, p. Paper 610.

Frank, A 2013, *The wounded storyteller: body, illness and ethics, 2nd edn* The University of Chicago Press, Chicago.

Fukui, S, Okada, S, Nishimoto, Y & Nelson-Becker, H 2011, 'The repeated appeal to return home in older adults with dementia: developing a model for practice', *Journal of Cross-Cultural Gerontology*, vol. 26, no. 1, pp. 39-54.

Gardner, F 2011, *The Car, the rain, and meaningful conversation: reflexivity and practice*, ProQuest Ebook Central, http://ebookcentral.proquest.com/lib/latrobe/detail.action?docID=908964. edn, Columbia University Press, Downloaded 17/5/18.

Gatens, M 1996, *Imaginary bodies: ethics, power and corporeality*, Routledge, London ; New York.

Geertz, C 1988, *Works and lives: the anthropologist as author*, Stanford University Press, Stanford, CA.

Gerritsen, D, Oyebode, J & Gove, D 2018, 'Ethical implications of the perception and portrayal of dementia', *Dementia*, vol. 17, no. 5, pp. 596–608.

Gilleard, C & Higgs, P 2010, 'Aging without agency: theorizing the fourth age', *Aging & Mental Health*, vol. 14, no. 2, pp. 121-8

—— 2017, 'An enveloping shadow? The role of the nursing home in the social imaginary of the fourth age', in S Chivers & U Kriebernegg (eds), *Care Home Stories*, Transcript Verlag, pp. 229-46.

Gilligan, C 1982, *In a different voice: psychological theory and women's development*, Harvard University Press, Cambridge, MA.

Gilligan, C, Spencer, R, Weinberg, K & Bertsch, T 2003, 'On the listening guide: a voice-centred relational model', in P Carmic, R JE & L Yardley (eds), *Qualitative research in psychology: expanding perspectives in methodology and design*, American Psychological Association, Washington DC, pp. 157-72.

Gilmour, J & Brannelly, T 2010, 'Representations of people with dementia – subaltern, person, citizen', *Nursing Inquiry*, vol. 17, no. 3, pp. 240–7.

Gjernes, T & Maseide, P 2020, 'Maintaining ordinariness in dementia care', *Sociology of Health & Illness*, vol. 42, no. 8, pp. 1771–84.

Godwin, B & Poland, F 2015, 'Bedlam or bliss? Recognising the emotional self-experience of people with moderate to advanced dementia in residential and nursing care', *Quality in Ageing and Older Adults*, vol. 16, no. 4, pp. 235-48.

Goldsmith, M 1996, *Hearing the voice of the person with dementia opportunities and obstacles*, Jessica Kingsley Publishers, London and Bristol.

Goodall, M 2014, 'Caring for people with dementia: a sign of the kingdom', *International Journal of Practical Theology*, vol. 18, no. 2, pp. 248-63.

Gove, D, Small, N, Downs, M & Vernooij-Dassen, M 2017, 'General practitioners' perceptions of the stigma of dementia and the role of reciprocity', *Dementia*, vol. 16, no. 7, pp. 948-64.

Graham, E 2013, 'Is practical theology a form of action research? ', *International Journal of Practical Theology*, vol. 17, no. 1, pp. 148–78.

Graham, E, Walton, H & Ward, F 2007, *Theological reflection sources*, SCM Press, London.

Gray, D 2014, 'Ethnography and participant observation', in *Doing research in the real world*, Sage, Los Angeles, pp. 438-65.

Greenblat, C 2011, *Love, loss and laughter: seeing Alzheimer's differently* Lyons Press, Connecticut.

Grenier, A, Lloyd, L & Phillipson, C 2017, 'Precarity in late life: rethinking dementia as a 'frailed' old age', *Sociology of Health & Illness*, vol. 39, no. 2, pp. 318–30.

Grenier, A & Phillipson, C 2013, 'Rethinking agency in later life: structural and interpretive processes', in J Baars, J Dohmen, A Grenier & C Phillipson (eds), *Ageing, meaning and social structure: connecting critical and humanistic gerontology*, Policy Press, Bristol, pp. 55-80.

Groves, A, Thomson, D, McKellar, D & Procter, N 2017, *The Oakden Report*, SA Health, Department for Health and Ageing, Adelaide, South Australia.

Harrington, A, Williamson, V & Goodwin-Smith, I 2018, 'Understanding the diverse forms of spiritual expression of older people in residential aged care in Australia', *Journal of Religion and Health*, vol. 5.

Hartmann, C, Mills, W, Pimentel, C, Palmer, J, Allen, R, Zhao, S, Wewiorski, N, Sullivan, J, Dillon, K, Clark, V, Berlowitz, D & Snow, A 2018, 'Impact of intervention to improve nursing home resident–staff interactions and engagement', *The Gerontologist*, vol. 58, no. 4, pp. e291-e301.

Haunch, K, Downs, M & Oyebode, J 2022, 'Leading by example: nursing home staff experiences of what facilitates them to meaningfully engage with residents with advanced dementia', *International Journal of Geriatric Psychiatry*, vol. 37, no. 9, pp. 1-13.

Heggestad, A, Nortvedt, P & Slettebø, A 2012, 'The importance of moral sensitivity when including persons with dementia in qualitative research', *Nursing Ethics*, vol. 20, no. 1, pp. 30–40.

—— 2015, 'Dignity and care for people with dementia living in nursing homes', *Dementia*, vol. 14, no. 6, pp. 825–41.

Helleberg, K & Hauge, S 2014, '"Like a dance": performing good care for persons with dementia living in institutions', *Nursing Research and Practice*, vol. Article ID 905972, pp. 1-7.

Hennelly, N, Cooney, A, Houghton, C & O'Shea, E 2021, 'Personhood and dementia care: a qualitative evidence synthesis of the perspectives of people with dementia', *The Gerontologist*, vol. 61, no. 3, pp. e85-e100.

Hennelly, N & O'Shea, E 2022, 'A multiple perspective view of personhood in dementia', *Ageing & Society*, vol. 42, no. 9, pp. 2103-21.

Herman, B 1997, 'The bricoleur revisited', in D Winterthur (ed.), *American material culture : the shape of the field*, University of Tennessee Press Knoxville, USA.

Hermans, H 1996, 'Voicing the self: from information processing to dialogical interchange', *Psychological Bulletin*, vol. 119, no. 1, pp. 31-50.

Heshusius, L 1994, 'Freeing ourselves from objectivity: managing subjectivity or turning toward a participatory mode of consciousness?', *Educational Researcher*, vol. 23, no. 3, pp. 15-22.

Heyl, B 2001, 'Ethnographic interviewing', in P Atkinson, A Coffey, S Delamont, J Lofland & L Lofland (eds), *Handbook of ethnography*, Sage, London, pp. 369-83.

Higgs, P & Gilleard, C 2015, *Rethinking old age: Theorizing the fourth age*, Macmillan Education Palgrave, London.

—— 2016, 'Interrogating personhood and dementia', *Aging & Mental Health*, vol. 20, no. 8, pp. 773-80.

—— 2017, 'Ageing, dementia and the social mind: past, present and future perspectives', *Sociology of Health and Ilness*, vol. 39, no. 2, pp. 175-81.

—— 2021, 'Fourth Ageism: Real and Imaginary Old Age', *Societies*, vol. 11, no. 1, p. 12.

Hillier, T & Stokes, G 2012, 'Meaningful moments', *Journal of Dementia Care*, vol. 20, no. 6, pp. 27-9.

Hosie, A, Kochovska, S, Ries, N, Gilmore, I, Parker, D, Sinclair, C, Sheehan, C, Collier, A, Caplan, G, Visser, M, Xu, X, Lobb, E, Sheahan, L, Brown, L, Lee, W, Sanderson, C, Amgarth-Duff, I, Green, A, Edwards, L & Agar, M 2021, 'Older persons’ and their caregivers’ perspectives and experiences of research participation with impaired decision-making capacity: a scoping review', *The Gerontologist*, vol. 20 no. 20, pp. 1-11.

Howarth, C 2014, 'Encountering the ageing body in modernity: fear, vulnerability and “contamination”', *Journal for Cultural Research*, vol. 18, no. 3, pp. 223-48.

Hubbard, G, Downs, M & Tester, S 2003, 'Including older people with dementia in research: challenges and strategies', *Aging & Mental Health*, vol. 7, no. 5, pp. 351-62.

Hudson, R 2003, 'Ageing and the Trinity holey, wholly, holy?', in A Jewell (ed.), *Ageing, spirituality and well-being*, Jessica Kingsley Publishers, London, pp. 86-100.

—— 2007, 'Dementia: nurturing the spirit', *Spirituality and Health International*, vol. 8, no. 1, pp. 20-30.

—— 2012, 'Transforming communities in residential aged care', *Journal of Religion, Spirituality and Aging*, vol. 24, no. 1/2, pp. 55-67.

—— 2016, 'God's faithfulness and dementia: Christian theology in context', *Journal of Religion Spirituality & Aging*, vol. 28, no. 1-2, pp. 50-67.

Hudson, R & Richmond, J 2000, *Living, dying caring: life and death in a nursing home, 2nd edn*, Ausmed Publications, Melbourne.

Hughes, J 2011, *Thinking through dementia*, Oxford University Press, Oxford.

Hughes, J, Volicer, L & van der Steen, J 2018, 'Complexity and gaps: the high-hanging fruit of dementia and palliative care research', *Palliative Medicine*, vol. 32, no. 3, pp. 591-3.

Hulme, B April, 2023, 'Seminar Reflective practice for shalom-shaped chaplaincy and spiritual care', in Tabor College, Adelaide.

Hydén, L 2011a, 'Narrative collaboration and scaffolding in dementia', *Journal of Aging Studies*, vol. 25, pp. 339–47.

—— 2011b, 'Non-verbal vocalizations, dementia and social interaction', *Communication & Medicine*, vol. 8, no. 2, pp. 135–44.

—— 2013, 'Story telling in dementia: embodiment as a resource', *Dementia*, vol. 12, no. 3, pp. 359–67.

Hydén, L & Örulv, L 2009, 'Narrative and identity in Alzheimer's disease: a case study', *Journal of Aging Studies*, vol. 23, pp. 205–14.

—— 2010, 'Interaction and narrative structure in dementia', in D Schiffrin, A Fina & A Nylund (eds), *Telling stories: language, narrative and social life*, Georgetown University Press, pp. 149-60.

Joffe, H 2012, 'Thematic analysis', in D Harper & A Thompson (eds), *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners, 1st edn*, John Wiley & Sons, Ltd., On-line, pp. 209-23.

Johnson, A, Chang, E, Daly, J, Harrison, K, Noel, M, Hancock, K & Easterbrook, S 2009, 'The communication challenges faced in adopting a palliative care approach in advanced dementia', *International Journal of Nursing Practice*, vol. 15, no. 5, pp. 467-74.

Jones, H 2010, 'Being really there and really aware. Ethics, politics and representation', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, pp. 28-41.

Jones, J & Smith, J 2017, 'Ethnography: challenges and opportunities', *Evidence Based Nursing British Medical Journal*, vol. 20 no. 4, pp. 98-100.

Josephs, I 2002, '"The Hopi in Me". The construction of a voice in the dialogical self from a cultural psychological perspective', *Theory & Psychology*, vol. 12, no. 2, pp. 162-73.

Katz, A & Shotter, J 1996, 'Hearing the patient's 'voice': toward a social poetics in diagnostic interviews', *Social Science and Medicine*, vol. 43, no. 6, pp. 919-31.

Keating, E 2001, 'The Ethnography of communication', in P Atkinson, A Coffey, S Delamont, J Lofland & L Lofland (eds), *Handbook of ethnography, Sage, London*, Sage, London.

Keller, J & Kittay, E 2017, 'Feminist ethics of care', in A Garry, S Khader & A Stone (eds), *The Routledge Companion to Feminist Philosophy*, Taylor & Francis Group, pp. 540-56.

Kelly, F 2014, 'Bodywork in dementia care: recognising the commonalities of selfhood to facilitate respectful care in institutional settings', *Ageing & Society*, vol. 34, pp. 1073-109.

Kelly, F & Innes, A 2013 'Human rights, citizenship and dementia care nursing', *International Journal of Older People Nursing*, vol. 8, pp. 61–70.

Kevern, P 2015, 'The spirituality of people with late-stage dementia: a review of the research literature, a critical analysis and some implications for person-centred spirituality and dementia care', *Mental Health, Religion & Culture*, vol. 18, no. 9, pp. 765-76.

Killick, J & Allan, K 2010, *Communication and the care of people with dementia*, Open University Press, Buckingham.

Kincheloe, J 2001, 'Describing the bricolage: conceptualizing a new rigor in qualitative research', *Qualitative Inquiry*, vol. 7, no. 6, pp. 679-92.

Kincheloe, J, McLaren, P & Steinber, R 2011, 'Critical pedagogy and qualitative research: moving to the bricolage', in N Denzin & Y Lincoln (eds), *The sage handbook of qualitative research, 4th edn*, Sage Publications, Inc., Los Angeles, pp. 163-77.

King, M 2021, *ABC Radio National Conversations with Sarah Kanowski, 28/02/2021*

Kinghorn, W 2016, '"I Am Still With You": Dementia and the Christian wayfarer', *Journal of Religion Spirituality & Aging*, vol. 28, no. 1-2, pp. 98-117.

Kitwood, T 1997, *Dementia reconsidered: the person comes first*, Open University Press, Buckingham.

—— 2007, 'Culture of care: traditions and change (1995)', in C Baldwin & A Capstick (eds), *Tom Kitwood on dementia: a reader and critical commentary*, Open University Press, Berkshire, England, pp. 306-13.

Kitwood, T & Bredin, K 1992, 'Towards a theory of dementia care: personhood and well-being', *Ageing and Society*, vol. 12, pp. 269-87.

Koch, T 2015, 'Improving Health and well being researching alongside marginalized people across diverse domains', in H Bradbury (ed.), *The sage handbook of action research*, Sage, pp. 325-36.

Koch, T & Crichton, J 2007, 'Innovative approaches to living with dementia', in M Nolan, E Hanson & G Gordon (eds), *User participation research in health and social care*, McGraw-Hill Education, ProQuest Ebook Central, pp. 89-103.

Koch, T & Harrington, A 1998, 'Reconceptualizing rigour: the case for reflexivity', *Journal of Advanced Nursing*, vol. 28, no. 4, pp. 882-90.

Kolanowski, A & Barksdale, B 2014, 'Keeping the older adult's voice central in research and practice', *JOURNAL OF GERONTOLOGICAL NURSING*, vol. 40, no. 10, pp. 3-4.

Kontos, P 2004, 'Ethnographic reflections on selfhood, embodiment and Alzheimer's disease', *Ageing & Society*, vol. 24, pp. 829–49.

—— 2005, 'Embodied self-hood in Alzheimer's disease: rethinking person-centred care', *Dementia*, vol. 4, no. 4, pp. 553-70.

—— 2006, 'Embodied selfhood: redefining agency in Alzheimer's disease', in E Tulle (ed.), *Old age and agency*, Nova Science Publishers Inc., New York, pp. 105-21.

—— 2011, 'Rethinking sociability in long-term care: an embodied dimension of selfhood', *Dementia*, vol. 11, no. 3, pp. 329–46.

—— 2012, *Alzheimer expressions or expressions despite Alzheimer's? Philosophical reflections on selfhood and embodiment*, http://occasion.stanford.edu/node/102 edn, Stanford University, 14/10/2021.

Kontos, P & Grigorovich, A 2018, 'Integrating citizenship, embodiment, and relationality: towards a reconceptualization of dance and dementia in long-term care', *Journal of Law, Medicine & Ethics*, vol. 46, no. 3, pp. 717-23.

Kontos, P, Grigorovich, A, Dupuis, S, Jonas-Simpson, C, Mitchell, G & Gray, J 2020, 'Raising the curtain on stigma associated with dementia: fostering a new cultural imaginary for a more inclusive society', *Critical Public Health*, vol. 30, no. 1, pp. 91-102.

Kontos, P & Martin, W 2013, 'Embodiment and dementia: exploring critical narratives of selfhood, surveillance, and dementia care', *Dementia*, vol. 12, no. 3, pp. 288–302.

Kontos, P, Miller, K-L & Kontos, A 2017, 'Relational citizenship: supporting embodied selfhood and relationality in dementia care', *Sociology of Health & Illness*, vol. 39, no. 2, pp. 182–98.

Kontos, P, Miller, K-L, Mitchell, G & Stirling-Twist, J 2017, 'Presence redefined: the reciprocal nature of engagement between elder-clowns and persons with dementia', *Dementia*, vol. 16, no. 1, pp. 46-66.

Kontos, P, Radnofsky, M, Fehr, P, Belleville, M, Bottenberg, F, Fridley, M, Massad, S, Grigorovich, A, Carson, J, Rogenski, K, Carpenter, K, Dupuis, S, Battalen, J, McDonagh, D, Fassbender, K & Whitehouse, P 2021, 'Separate and unequal: a time to reimagine dementia', *Journal of Alzheimer's Disease*, vol. 80, no. 4, pp. 1395-9.

Kristjanson, L 2006, ' Palliative approach to spirituality in residential aged care', *Journal of Religion, Spirituality and Aging*, vol. 18, no. 4, pp. 189-205.

Laverick, W 2010, 'Accessing inside ethical dilemmas and pragmatic compromises ', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, pp. 73-88

Laws, G 1995 'Understanding ageism: lessons from feminism and postmodernism', *The Gerontologist*, vol. 35, no. 1, pp. 112-8.

Lee, R, Bamford, C, Poole, M, McLellan, E, Exley, C & Robinson, L 2017, 'End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice', *PLoS One*, vol. 12, no. 6.

LeVasseur, A 2021, 'Effects of social isolation on a long-term care resident with dementia and depression during the COVID-19 pandemic', *Geriatric Nursing*, vol. 42, pp. 780-1.

Levi-Strauss, C 1966, *The savage mind (La pensee sauvage)*, Weidenfeld and Nicolson, London.

Liamputtong, P 2013, 'Ethnography', in P Liamputtong (ed.), *Qualitative Research Methods 4th edn*, Oxford University Press, Melboure, pp. 158-79.

—— 2022, 'Social inclusion, research, and practices in the health and social sciences: setting the scene', in P Liamputtong (ed.), *Handbook of social inclusion*, Springer Nature Switzerland AG, pp. 1-17.

Light, D 2010, 'The Final stage? Writing up ethnographic research', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, pp. 173-86.

Lillekroken, D, Hauge, S & Slettebø, Å 2017, 'The meaning of slow nursing in dementia care', *Dementia*, vol. 16, no. 7, pp. 930-47.

Lincoln, Y 1995, 'Emerging criteria for quality in qualitative and interpretive inquiry', *Qualitative Inquiry*, vol. 1, pp. 275-89.

—— 2001, 'An emerging new bricoleur: promises and possibilities—a reaction to Joe Kincheloe's "Describing the bricoleur"', *Qualitative Inquiry*, vol. 7, no. 6, pp. 693-6.

Lincoln, Y, Lynham, S & Gruba, E 2005, 'Paradigmatic controversies, contradictions and emerging confluences revisited', in N Denzin & Y Lincoln (eds), *The Sage handbook of qualitative research 3rd edn*, SAGE Publications, Inc, Thousand Oaks, pp. 97-128.

Lindemann, H 2010, 'Holding one another (well, wrongly, clumsily) in a time of dementia', in E Kittay & L Carlson (eds), *Cognitive disability and its challenge to moral philosophy*, Wiley, On-line, pp. 161-9.

Lloyd, L, Calnan, M, Cameron, A, Seymour, J & Smith, R 2014, 'Identity in the fourth age: perseverance, adaptation and maintaining dignity', *Ageing & Society*, vol. 34, pp. 1-19.

Lombard, D 2021, 'Person-centred communication in long-term care with older people: a scoping review: managing community care', *Journal of Integrated Care*, vol. 29, no. 3, pp. 306-33.

Louw, D 2011, 'Noetics and the notion of "ubuntu"-thinking within an intercultural hermeneutics and philosophical approach to theory formation in practical theology', *International Journal of Practical Theology*, vol. 15, pp. 173 – 92.

Luckett, T, Luscombe, G, Phillips, J, Beattie, E, Chenoweth, L, Davidson, P, Goodall, S, Pond, D, Mitchell, G & Agar, M 2019, 'Australian long-term care personnel's knowledge and attitudes regarding palliative care for people with advanced dementia', *Dementia*, vol. 0, no. 0, pp. 1–17.

Ludwin, K & Capstick, A 2015, 'Using participatory video to understand diversity among people with dementia in long-term care', *Journal of Psychological Issues in Organizational Culture*, vol. 5, no. 4, pp. 30-8.

Luff, R, Laybourne, A, Ferreira, Z & Meyer, J 2015, 'A guide to research with care homes', *Quality in Ageing and Older Adults*, vol. 16, no. 4, pp. 186-94.

Luttrell, W & Chalfen, R 2010, 'Lifting up voices of participatory visual research', *Visual Studies*, vol. 25, no. 3, pp. 197-200.

MacKinlay, E 1998, 'The spiritual dimension of ageing: meaning in life, response to meaning and well-being in ageing', PhD thesis, Latrobe University, Melbourne.

—— 2006, *Spiritual growth and care in the fourth age of life*, Jessica Kingsley Publishers, London.

MacKinlay, E & Trevitt, C 2012, *Finding meaning in the experience of dementia: the place of spiritual reminiscence work*, Jessica Kingsley Publishers, London.

Macquarrie, J 1977, *Principles of Christian theology*, SCM Press Ltd, London.

Majic, T, Pluta, J, Mell, T, Treusch, Y, Gutzmann, H & Rapp, M 2012, 'Correlates of agitation and depression in nursing home residents with dementia', *International Psychogeriatrics*, vol. 24, no. 7, pp. 1779-89.

Mansah, M, Coulon, L & Brown, P 2008, 'A mapper’s reflection on Dementia Care Mapping with older residents living in a nursing home', *International Journal of Older People Nursing*, vol. 3, pp. 113–20.

Marks, D & Yardley, L 2011, 'Content and thematic analysis', in D Marks & L Yardley (eds), *Research methods for clinical and health psychology*, Sage, London, pp. 56–68.

McFadden, S 2004, 'The Paradoxes of humor and the burdens of despair', *Journal of Religious Gerontology*, vol. 16, no. 3-4, pp. 13-27.

McFadden, S & McFadden, J 2012, *Aging together: dementia,friendship and flourishing communities*, John Hopkins University Press, Baltimore.

McGovern, J 2016, 'When actions speak louder than words: extending the reach of qualitative data collecting', *Global Qualitative Nursing Research*, vol. 3, pp. 1-7.

McKillop, J & Wilkinson, H 2004, 'Make it easy on yourself: advice to researchers from someone with dementia on being interviewed', *Dementia*, vol. 3, no. 2, pp. 117-25.

McParland, P, Kelly, F & Innes, A 2017, 'Dichotomising dementia: is there another way?', *Sociology of Health & Illness*, vol. 39, no. 2, pp. 258–69.

Meaningful Ageing Australia 2016, *National guidelines for spiritual care in aged care*, Meaningful Ageing Australia, viewed 14/02/2020, <https://meaningfulageing.org.au/product/national-guidelines-for-spiritual-care-in-aged-care/>.

Mesman, J 2007, 'Disturbing observations as a basis for collaborative research ', *Science as Culture*, vol. 16, no. 3, pp. 281-95.

—— 2011, 'Resources of strength: an exnovation of hidden competences to preserve patient safety', in E Rowley & J Waring (eds), *A socio-cultural perspective on patient safety*, Ashgate, Surrey, pp. 71-92.

Meyer, J, Heath, H, Holman, C & Owen, T 2006, 'Moving from victim blaming to an appreciative inquiry: exploring quality of life in care homes', *Quality in Ageing*, vol. 7, no. 4, pp. 27-36.

Miller-McLemore, B 1996, 'The living human web: pastoral theology at the turn of the century', in J Stevenson Moessner (ed.), *Through the eyes of women: insights for pastoral care*, Fortress Press, Minneapolis, pp. 9-26.

Milne, A 2011, 'Living with dementia in a care home: capturing the experiences of residents', *Quality in Ageing and Older Adults*, vol. 12, no. 2, pp. 76-85.

Milte, R, Shulver, W, Killington, M, Bradley, C, Ratcliffe, J & Crotty, M 2016, 'Quality in residential care from the perspective of people living with dementia: the importance of personhood', *Archives of Gerontology and Geriatrics*, vol. 63, pp. 9–17.

Mitchell, G, McCormack, B & McCance, T 2016, 'Therapeutic use of dolls for people living with dementia: a critical review of the literature', *Dementia*, vol. 15, no. 5, pp. 976–1001.

Mok, Z & Muller, N 2014, 'Staging casual conversations for people with dementia', *Dementia*, vol. 13, no. 6, pp. 834–53.

Moos, I 2011, 'Humour, irony and sarcasm in severe Alzheimer's dementia - a corrective to retrogenesis?', *Ageing & Society*, vol. 31, no. 2, pp. 328-46.

Morell, C 2003, 'Empowerment and long-living women: return to the rejected body', *Journal of Aging Studies*, vol. 17, pp. 69–85.

Moyle, W, Fetherstonhaugh, D, Greben, M, Beattie, E & AusQoL Group, G 2015, 'Influencers on quality of life as reported by people living with dementia in long term care: a descriptive exploratory approach', *BioMedical Central (BMC) Geriatrics*, vol. 15, no. 50, pp. 1-10.

Muller, N & Mok, Z 2014, '"Getting to know you": situated and distributed cognitive effort in conversations and dementia', in R Schrauf & N Muller (eds), *Dialogue and dementia: cognitive and communicative resources for engagement*, Psychology Press, New York, pp. 61-86.

Muller, N & Schrauf, R 2014, 'Conversation as cognition', in R Schrauf & N Muller (eds), *Dialogue and dementia: cognitive and communicative resources for engagement*, Psychology Press, New York, pp. 3-26.

Murphy, E, Froggatt, K, Connolly, S, O'Shea, E, Sampson, E, Casey, D & Devane, D 2016, 'Palliative care interventions in advanced dementia', *Cochrane Database Systematic Reviews*, vol. 12, p. Cd011513.

National Health and Medical Research Council (NHMRC) 2007 (Updated 2018), *National statement on ethical conduct in human research*, The National Health and Medical Research Council, the Australian Research Council and Universities Australia, Commonwealth of Australia, Canberra.

—— 2018, *Australian code for the responsible conduct of research*, Commonwealth of Australia, Canberra.

NATSEM 2018, *Dementia Prevalence Data 2018-2058*, Dementia Australia, Canberra.

NATSEM, Brown, L, Hansnata, E & La, H 2017, *Economic cost of dementia in Australia 2016-2056: NATSEM report prepared for Alzheimer’s Australia*, The Institute for Governance and Policy Analysis, University of Canberra.

Nicholls, D, Chang, E, Johnson, A & Edenborough, M 2013, 'Touch, the essence of caring for people with end-stage dementia: a mental health perspective in Namaste Care', *Aging and Mental Health*, vol. 17, no. 5, pp. 571-8.

Nolan, M, Davies, S, Brown, J, Keady, J & Nolan, J 2004, 'Beyond ‘person-centred’ care: a new vision for gerontological nursing', *International Journal of Older People Nursing in association with Journal of Clinical Nursing*, vol. 13, no. 3a, pp. 45-53.

Nolan, M, Davies, S, Ryan, T & Keady, J 2008, 'Relationship-centred care and the ‘senses’ framework', *Journal of Dementia Care*, vol. 16, pp. 26-8.

Nolan, M, Ryan, T, Enderby, P & Reid, D 2002, 'Towards a more inclusive vision of dementia care practice and research', *Dementia*, vol. 1, no. 2, pp. 193-211.

Norberg, A, Ternestedt, B & Lundman, B 2017, 'Moments of homecoming among people with advanced dementia disease in a residential care facility', *Dementia*, vol. 16, no. 5, pp. 629-41.

Nouwen, H 1975, *Reaching out*, Doubleday & Company Incorporated, New York.

Novek, S & Wilkinson, H 2017, 'Safe and inclusive research practices for qualitative research involving people with dementia: a review of key issues and strategies', *Dementia*, vol. 0, no. 0, pp. 1-18.

—— 2019, 'Safe and inclusive research practices for qualitative research involving people with dementia: a review of key issues and strategies', *Dementia*, vol. 18, no. 3, pp. 1042-59.

Nowak, L & Davis, J 2007, 'A qualitative examination of the experience of sundowning', *Journal of Nursing Scholarship*, vol. 39, pp. 256-8.

Nowell, Z & Thornton, A 2011, 'The subjective experience of personhood in dementia care settings', *Dementia*, vol. 12, no. 4, pp. 394-409.

O'Connor, D, Phinney, A, Small, J, Purves, B, Perry, J, Drance, E, Donnelly, M, Chaudhury, H & Beattie, L 2007, 'Personhood in dementia care: developing a research agenda for broadening the vision', *Dementia*, vol. 16, no. 1, pp. 121-42.

O'Reilly, K 2009, *Key concepts in ethnography*, Sage, Los Angeles.

O'Rourke, H, Fraser, K, Duggleby, W & Keating, N 2018, 'The association of perceived conflict with sadness for long-term care residents with moderate and severe dementia', *Dementia*, vol. 17, no. 7, pp. 801-20.

Oliver, M *The Summer Day*, 25/06/2023, <https://www.loc.gov/programs/poetry-and-literature/poet-laureate/poet-laureate-projects/poetry-180/all-poems/item/poetry-180-133/the-summer-day/?loclr=blogpoe>.

Oudman, E & Veurink, B 2014, 'Quality of life in nursing home residents with advanced dementia: a 2-year follow-up', *Psychogeriatrics*, vol. 14, no. 4, pp. 235-40.

Oyebode, J & Parveen, S 2019, 'Psychosocial interventions for people with dementia: an overview and commentary on recent developments', *Dementia*, vol. 18, no. 1, pp. 8-35.

Palmer, J 2013, 'Preserving personhood of individuals with advanced dementia: lessons from family caregivers', *Geriatric Nursing*, vol. 34, no. 3, pp. 224-9.

Palmer, J, Smith, A, Paasche-Orlow, R & Fitchett, G 2020, 'Research literature on the intersection of dementia, spirituality, and palliative care: a scoping review', *Journal of Pain and Symptom Management*, vol. 60, no. 1, pp. 116-34.

Parker, S 2015, *Using critical thinking to enhance your higher degree*, Seminar presentation to PhD students, Flinders University.

Parse, R 1991, 'Human becoming: Parse's theory of nursing', *Nursing Science Quarterly*, vol. 5, no. 1 Spring, pp. 35-42.

Parsons, J 2022, *A question of age: women, ageing and the forever self*, HarperCollins Publishers, Australia.

Pattison, S 2013, *Saving face enfacement, shame, theology*, Ashgate Publishing Company, Farnham, Surrey.

Paver, J 1996, 'Formation and transformation in theological reflection', *Ministry, Society and Theology*, vol. 10, no. 2.

—— 2006, *Theological reflection and education for ministry The search for integration in theology*, Ashgate, Aldershot, Hampshire.

Peisah, C, Lawrence, G & Reutens, S 2011, 'Creative solutions for severe dementia with BPSD: a case of art therapy used in an inpatient and residential care setting', *International Psychogeriatrics*, vol. 23, no. 6, pp. 1011-3.

Pembroke, N 2019, 'Empathic and compassionate healthcare as a Christian spiritual practice', *Practical Theology*, vol. 12, no. 2, pp. 133-46.

Perkins, C, Egan, R, Llewellyn, R & Peterken, B 2015, 'Still living, loving, and laughing: spiritual life in the dementia unit', *Journal of Religion, Spirituality and Aging*, vol. 27, no. 4, pp. 270-87.

Phillipson, L & Hammond, A 2018, 'More than talking: a scoping review of innovative approaches to qualitative research involving people with dementia', *International Journal of Qualitative Methods*, vol. 17, no. 1, pp. 1-13.

Pickard, S 2014, 'Frail bodies: geriatric medicine and the constitution of the fourth age', *Sociology of Health & Illness*, vol. 36, no. 4, pp. 549-63.

Picken, F 2013, 'Ethnography', in M Walter (ed.), *Social Research Methods, 3rd edn*, Oxford University Press, Melbourne.

Pieper, M, Francke, A, van der Steen, J, Scherder, E, Twisk, J, Kovach, C & Achterberg, W 2016, 'Effects of a stepwise multidisciplinary intervention for challenging behavior in advanced dementia: a cluster randomized controlled trial', *Journal of American Geriatrics Society*, vol. 64, no. 2, pp. 261-9.

Pöllänen, S & Hirsimäki, R 2014, 'Crafts as memory triggers in reminiscence: a case study of older women with dementia', *Occupational Therapy in Health Care*, vol. 28, no. 4, pp. 410-30.

Prince, M, Comas-Herrera, A, Knapp, M, Guerchet, M & Karagiannidou, M 2016, *World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future*, Alzheimer's Disease International, London.

Prince, M, Wimo, A, Guerchet , M, Ali, GC, Wu, Y & Prina, M 2015, *The global impact of dementia: an analysis of prevalence, incidence, cost and trends*, Alzheimer's Disease International, London.

Puchalski, C, Vitillo, R, Hull, S & Reller, N 2014, 'Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference', *Journal of Palliative Medicine*, vol. 17, no. 6, pp. 642-56.

Puurveen, G, Phinney, A, Cox, S & Purves, B 2015, 'Ethical issues in the use of video observations with people with advanced dementia and their caregivers in nursing home environments', *Journal of Video Methodologies*, vol. 3, no. 2, pp. 16-26.

Quinn, C, Clare, L, Jelley, H, Bruce, E & Woods, B 2014, ''It's in the eyes': how family members and care staff understand awareness in people with severe dementia', *Aging & Mental Health*, vol. 18, no. 2, pp. 260-8.

Rayner, G & Warne, T 2016, 'Interpersonal processes and self-injury: a qualitative study using bricolage', *Journal of Psychiatric and Mental Health Nursing*, vol. 23, no. 1, pp. 54-65.

Reinders, H 2008, *Receiving the gift of friendship : profound disability, theological anthropology, and ethics*, Eerdmans, Ann Arbor, MI.

Reinharz, S 1997, 'Who am I? The need for a variety of selves in the field', in R Hertz (ed.), *Reflexivity and voice*, Sage Publications, Thousand Oaks, pp. 3-20.

Reisberg, B, Wegiel, J, Franssen, E & al. 2006, 'Clinical features of severe dementia: staging', in A Burns & B Winblad (eds), *Severe dementia*, John Wiley and Sons Ltd., London, pp. 83-116.

Rice, H, Howard, R & Huntley, J 2019, 'Professional caregivers' knowledge, beliefs and attitudes about awareness in advanced dementia: a systematic review of qualitative studies', *International Psychogeriatrics*, vol. 31, no. 11, pp. 1599-609.

Richard, L, OMI, 2000, *Living the hospitality of God*, Paulist Press, New York.

Richardson-Tench, M, Taylor, B, Kermode, S & Roberts, K 2014, 'Critical appraisal of research', in *Research in nursing: Evidence for best practice* 5th edn, Cengage, Australia, pp. 74-81.

Riessman, C 2002, 'Narrative analysis', in A Miles & M Huberman (eds), *The qualitative research companion*, Sage Publications, Inc., Thousand Oaks, CA, pp. 217-74.

—— 2008, *Narrative methods for the human sciences*, Sage Publications, Los Angeles.

Ringma, C 2008, 'God's spirit and the poor-towards an incarnational and integral missional spirituality', in C Catford (ed.), *Following fire: how the Spirit leads us to fight injustice*, Urban Neighbours of Hope, Springvale, Vic., Australia.

Rogers, J 2020, *The interpretivist lens – what design study as a method of inquiry can teach us*, 24/05/2023, Visualization Design Lab, University of Utah, <https://vdl.sci.utah.edu/blog/>.

Rohr, R 2018a, 'Becoming who you are', in *A Spring within us: a year of daily meditations*, SPCK, London, pp. 184-9.

—— 2018b, 'Paradox', in *A Spring within us: a year of daily meditations*, SPCK, London, pp. 235-42.

Royal Commission into Aged Care Quality and Safety 2021a, *Final Report Volume 1: Care, Dignity and Respect Overview by Commissioner Briggs*, Commonwealth Government of Australia, Canberra.

—— 2021b, *Final Report Volume 1: Preface and Overview- What is to be done? by Chair Pagone* Commonwealth Government of Australia, Canberra.

—— 2021c, *Final Report Volume 1: Summary by Chair Pagone and Commissioner Briggs*, Commonwealth Government of Australia, Canberra.

—— 2021d, *Final Report Volume 2: care, dignity and respect*, Commonwealth Government of Australia, Canberra.

Rumbold, B 2006, 'The spirituality of compassion: a public health response to ageing and end-of-life care', *Journal of Religion, Spirituality & Aging*, vol. 18, no. 2-3, pp. 31-44.

—— 2011, 'Health promoting palliative care and dying in old age', in M Gott & C Ingleton (eds), *Living with ageing and dying: palliative and end of life care for older people* Oxford University Press, Oxford, pp. 75-89.

Sabat, S 1994, 'Recognizing and working with remaining abilities: toward improving the care of Alzheimer's disease sufferers ', *American Journal of Alzheimer's Care and Related Disorders & Research*, vol. 9, no. 3, pp. 8-16.

—— 2002, 'Surviving manifestations of selfhood in Alzheimer's disease', *Dementia*, vol. 1, no. 1, pp. 25-36.

—— 2003, 'Some potential benefits of creating research partnerships with people with Alzheimer's disease', *Research Policy and Planning*, vol. 21, no. 2, pp. 5-13.

—— 2006, 'Mind, meaning and personhood in dementia: the effects of positioning', in J Hughes, S Louw & S Sabat (eds), *Dementia mind, meaning and person*, Oxford University Press, Oxford, pp. 287-382.

Sabat, S & Harré, R 1999, 'Positioning and recovery of social identity', in R Harré & L van Langenhove (eds), *Positioning theory: moral contexts of intentional action*, Blackwell Publishing Ltd., Oxford, pp. 87-101.

Sabat, S, Johnson, A, Swarbrick, C & Keady, J 2011, 'The ‘demented other’ or simply ‘a person’? Extending the philosophical discourse of Naue and Kroll through the situated self', *Nursing Philosophy*, vol. 12, no. 12, pp. 282–92.

Sabat, S & Lee, J 2011, 'Relatedness among people diagnosed with dementia: social cognition and the possibility of friendship', *Dementia*, vol. 11, no. 3, pp. 315–27.

Saleebey, D 1996, 'The Strengths perspective in social work practice: extensions and cautions', *Social Work*, vol. 41, no. 3, pp. 296-305.

—— 2009, *The Strengths perspective in social work, 5th edn*, Pearson Education, Boston, USA.

Sampson, E 2010, ' Palliative care for people with dementia', *British Medical Bulletin*, vol. 96, no. 1, pp. 159–74.

Sarantakos, S 2013, *Social research, 4th edn*, Palgrave Macmillan, Basingstoke, Hampshire.

Saunders, P, de Medeiros, K, Doyle, P & Mosby, A 2011, 'The discourse of friendship: mediators of communication among dementia residents in long-term care', *Dementia*, vol. 11, no. 3, pp. 347–61.

Saville-Troike, M 2003, *The ethnography of communication: an introduction 3rd edn* Blackwell Publishing, Malden, MA, USA.

Schmidt, H, Eisenmann, Y, Golla, H, Voltz, R & Perrar, K 2018, 'Needs of people with advanced dementia in their final phase of life: a multi-perspective qualitative study in nursing homes', *Palliative Medicine*, vol. 32, no. 3, pp. 657-67.

Schneider, J, Spencer, H, Morgner, C & Dening, T 2019, 'Facilitation of positive social interaction through visual art in dementia: a case study using video-analysis', *Ageing and Society*, vol. 39, no. 8, pp. 1731-51.

Schrauf, R & Iris, M 2014, '"What they're said to say": the discursive construction of Alzheimer's disease by older adults', in R Schrauf & M Muller (eds), *Dialogue and dementia: cognitive and communicative resources for engagement*, Taylor & Francis, New York, pp. 27-57.

Schussler Fiorenza, E 1983, *In Memory of her: a feminist theological reconstruction of Christian Origins*, SCM Press Ltd, London.

Scott Jones, J 2010, 'Origins and ancestors: a brief history of ethnography', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, pp. 13-27.

Scott Jones, J & Watt, S 2010, 'Introduction', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, pp. 3-12.

Scottish Dementia Working Group 2014, 'Core principles for involving people with dementia in research: innovative practice', *Dementia*, vol. 13, no. 5, pp. 680–5.

Sevenhuijsen, S 2003, 'The place of care the relevance of the feminist ethic of care for social policy', *Feminist Theory*, vol. 4, no. 2, pp. 179-97.

Shakespeare, T, Zeilig, H & Mittler, P 2017, 'Rights in mind: thinking differently about dementia and disability', *Dementia*, vol. 0, no. 0, pp. 1-14.

Shibazaki, K & Marshall, N 2017, 'Exploring the impact of music concerts in promoting well-being in dementia care', *Aging and Mental Health*, vol. 21, no. 5, pp. 468-76.

Shotter, J 1998, 'Telling of (not about) other voices: "real presences" within a text', *Concepts and transformation*, vol. 3, no. 1-2, pp. 77-96.

Sidtis, D & Kreiman, J 2011, 'In the beginning was the familiar voice: personally familiar voices in the evolutionary and contemporary biology of communication', *Integrative Psychological and Behavioral Science*, vol. 46, pp. 146–59

Silverman, D 2011, *Interpreting qualitative data 4th edn*, SAGE Publications Ltd, Los Angeles.

Simpson, J 2006, 'There’s no place like home: discovering homeplace in an aged care home a phenomenological study from a pastoral care/chaplaincy perspective', MMin thesis, Adelaide College of Divinity.

Slape, J 2019, 'They are still people: an ethnographic investigation into a reconfiguration of personhood practice in residential dementia care', PhD thesis, Flinders University.

Smyth, M 2015, *Drive Home Program* ABC Radio 891, Adelaide, 20/11/2015.

Squire, C, Andrews, M & Tamboukou, M 2013, 'Introduction: what is narrative research?', in M Andrews, C Squire & M Tamboukou (eds), *Doing narrative research 2nd edn*, Sage, London, pp. 1-26.

Stacpoole, M, Hockley, J, Thompsell, A, Simard, J & Volicer, L 2015, 'The Namaste Care programme can reduce behavioural symptoms in care home residents with advanced dementia', *International Journal of Geriatric Psychiatry*, vol. 30, no. 7, pp. 702-9.

Stončikaitė, L 2021, 'Care, dementia, and the fourth age in Erica Jong's later work', *The Gerontologist*.

Swaffer, K 2014, 'Dementia: stigma, language and dementia friendly', *Dementia*, vol. 13, no. 6, pp. 709–16.

—— 2016, *What the hell happened to my brain? Living beyond dementia*, Jessica Kingsley Publishers, London.

Swinton, J 2012a, *Dementia Living in the memories of God*, Willian B. Eerdmans Publishing Company, Grand Rapids, Michigan.

—— 2012b, 'From inclusion to belonging: a practical theology of community, disability and humanness', *Journal of Religion, Disability & Health*, vol. 16, no. 2, pp. 172-90.

Swinton, J & Mowat, H 2006, *Practical theology and qualitative research*, SCM, London.

Taherdoost, H 2016, 'Sampling methods in research methodology: how to choose a sampling technique for research', *International Journal of Academic Research*, vol. 5, no. 2, pp. 18-27.

The Office of Parliamentary Counsel 2021, *Quality of Care Principles 2014 made under section 96-1 of the Aged Care Act 1997* Part 5, Canberra.

Thorne, S 2016, *Interpretive description: qualitative research for applied practice 2nd edn*, Routledge, New York.

Tronto, J 1993, *Moral boundaries: a political argument for an ethic of care*, Routledge, New York.

Tuckett, A 2007, 'The meaning of nursing-home: 'Waiting to go up to St. Peter, OK! Waiting house, sad but true' — an Australian perspective', *Journal of Aging Studies*, vol. 21, pp. 119–33.

UK Alzheimer's Society 2023, *About dementia symptoms and diagnosis*, Alzheimers Assocation viewed 11/08/23, <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/later-stages-dementia#content-start>.

USA Alzheimer's Association 2020, *Stages of Alzheimer's*, Alzheimer's Association, viewed 19/02/2021, <https://www.alz.org/alzheimers-dementia/stages>.

van Amerongen, Y 2019, *The "dementia village" that's redefining elder care* https://www.bing.com/videos/search?q=ted+talk+dementia+village&view=detail&mid=D545437674506184C835D545437674506184C835&FORM=VIRE, viewed 8/10/2021.

van der Steen, J, Lemos Dekker, N, Gijsberts, M, Vermeulen, H, Mahler, M & The, B 2017, 'Palliative care for people with dementia in the terminal phase: a mixed-methods qualitative study to inform service development', *BioMedical Central (BMC) Palliative Care*, vol. 16, no. 1, pp. 1-14.

van Langenhove, L & Harré, R 1999, 'Introducing positoning theory', in R Harré & L van Langenhove (eds), *Positioning theory: moral contexts of intentional action*, Blackwell publishing Ltd. , Oxford, pp. 14-31.

van Manen, M 1990, *Researching lived experience: human science for an action sensitive pedagogy*, State University of New York Press, London, Ontario.

Victor, C 2012, 'Loneliness in care homes: a neglected area of research?', *Aging Health*, vol. 8, no. 6, pp. 637–46.

Victor, C & Sullivan, M 2015, 'Loneliness and isolation', in J Twigg & W Martin (eds), *Routledge handbook of cultural gerontology*, Taylor & Francis Group.

Vigliotti, A, Chinchilli, V & George, D 2019, 'Evaluating the benefits of the TimeSlips creative storytelling program for persons with varying degrees of dementia severity', *American Journal of Alzheimer's Disease & Other Dementias®*, vol. 34, no. 3, pp. 163-70.

Volicer, L 2016, 'Fear of Dementia', *Journal of the American Medical Directors Association*, vol. 17 (2016) pp. 875-8.

Walmsley, B & McCormack, L 2016, 'Stigma, the medical model and dementia care: psychological growth in senior health professionals through moral and professional integrity', *Dementia*, vol. 15, no. 6, pp. 1685–702.

—— 2017, 'Severe dementia: relational social engagement (RSE) during family visits', *Aging & Mental Health*, vol. 21, no. 12, pp. 1262-71.

Ward, R, Campbell, S & Keady, J 2016, ''Gonna make yer gorgeous': everyday transformation, resistance and belonging in the care-based hair salon', *Dementia*, vol. 15, no. 3, pp. 395-413.

Watson, J 2016, 'Developing the senses framework to support relationship-centred care for people with advanced dementia until the end of life in care homes', *Dementia*, vol. 0, no. 0, pp. 1-22.

—— 2019, 'Developing the Senses Framework to support relationship-centred care for people with advanced dementia until the end of life in care homes', *Dementia*, vol. 18, no. 2, pp. 545–66.

Watt, S 2010, 'Leaving the field', in J Scott Jones & S Watt (eds), *Ethnography in social science practice*, Routledge, London, p.??

Watt, S & Scott Jones, J 2010, 'Let's look inside: doing participant observation', in J Scott Jones & J Watt (eds), *Ethnography in social science practice*, Routledge, London.

Wendell, S 1996 *The rejected body: feminist philosophical reflections on disability*, Routledge, New York.

Westerhof, G & Tulle, E 2007, 'Meanings of ageing and old age: discursive contexts, social attitudes and personal identities ', in J Bond, S Peace, F Dittmann-Kohli & G Westerhof (eds), *Ageing in Society Eurpoean Perspectives on Gerontology 3rd edn*, Sage, London, pp. 235-54.

Whittemore, R & Knafl, K 2005, 'The integrative review: updated methodology', *Journal of Advanced Nursing*, vol. 52, no. 5, pp. 546-53.

WHO 2012, *Dementia: a public health priority*, World Health Organization, Geneva.

—— 2017, *Global action plan on the public health response to dementia 2017–2025*, World Health Organization, viewed 13/02/2021, <https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf;jsessionid=4DA480FA93471AC53988E52B35F416D8?sequence=1>.

—— 2020, *Dementia fact sheets*, viewed 13/02/2021 <https://www.who.int/news-room/fact-sheets/detail/dementia>.

—— 2021, *Dementia fact sheets*, viewed 4/06/2022, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

—— 2023, *Dementia facts sheets*, viewed 26/08/2023, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

Wilkinson, H, Bowes, A, Bruce, E, Clarke, C & Downs, M 2015, 'Including people with dementia in research: methods and motivations', in H Wilkinson (ed.), *The perspectives of people with dementia: research methods and motivations*, Jessica Kingsley, London, pp. 9-24.

Williams, K 2011, 'Elder speak in institutional care for older adults', in P Backhaus (ed.), *Communication in elderly care Cross cultural perspectives*, Bloomsbury, London, pp. 1-19.

Williams, V, Webb, J, Read, S, James, R & Davis, H 2020, 'Future lived experience: inclusive research with people living with dementia', *Qualitative Research in Psychology*, vol. 20, no. 5, pp. 721–40.

Wolverson, EL, Clarke, C & Moniz-Cook, ED 2016, 'Living positively with dementia: a systematic review and synthesis of the qualitative literature', *Aging & Mental Health*, vol. 20, no. 7, pp. 676-99.

Woźnica, A 2019, 'Imago Dei in people with profound intellectual disabilities', *Theologica Xaveriana*, vol. 69, no. 188.

Wynn, R & Khayum, B 2015, 'Developing personally relevant goals for people with moderate to severe dementia', *Seminars in Speech & Language*, vol. 36, no. 3, pp. 199-208.

Yancey, K & Spooner, M 1994, 'Concluding the text: notes towards a theory and the practice of voice', in K Yancey (ed.), *Voices on voice: perspectives, definitions, inquiry*, National Council of Teachers of English, Urbana, Illinois, pp. 298-314.

Yardley, A 2019, 'Bricolage as Method', in P Atkinson, S Delamont, A Cernat, J Sakshaug & R William (eds), *Sage Research Methods*, Sage.

Yeo, C, Lim, W, Chan, M, Ho, X, Anthony, P, Han, H & Chong, M 2016, 'Severe Impairment Rating Scale: a useful and brief cognitive assessment tool for advanced dementia for nursing home residents', *American Journal of Alzheimers Disease and Other Dementias*, vol. 31, no. 1, pp. 87-96.

Young, J, Orange, J & Lind, C 2019, 'What is stigma?', *World Alzheimer's report 2019: attitudes to dementia*, pp. 17-20.

Zeiler, K 2014, 'A philosophical defense of the idea that we can hold each other in personhood: intercorporeal personhood in dementia care', *Medicine, Health Care, and Philosophy*, vol. 17, no. 1, pp. 131-41.

Zubrick, A 2016, 'Epiphanies: small miracles in everyday experiences of dementia', *Journal of Religion, Spirituality & Aging*, vol. 28, no. 1-2, pp. 37-49.

Zwakhalen, SM, van der Steen, JT & Najim, MD 2012, 'Which score most likely represents pain on the observational PAINAD pain scale for patients with dementia?', *Journal of American Medical Directors Association*, vol. 13, no. 4, pp. 384-9.

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APPENDIX 1 SUMMARY OF CRITICAL APPRAISAL OF FINAL RESEARCH ARTICLES (CHAPTER 3)

Article No.	Author(s) and Date	Q1 Aim	Q2 Method-ology	Q3 Design	Q4 Sample	Q5 Data Collection	Q6 Role of Res'er	Q7 Ethics	Q8 Data Analysis	Q9 Findings	Q10 Value
1	Allison, Balbino & Covinsky (2019)	√	√	√	√	Observn &interviews	√	√	√ Thematic	√	√√
2	Batra et al (2016)	√	√	√	X Mod	Mod	√	√	√	√	√
3	Berendonk & Caine (2016)	X	Grounded theory	Mod	√	√	√	X	Moderate	√	√
4	Bourbonnais & Duchame (2015)	√	Ethnography	√	√	2nd Anal	√	X	√	√	√
5	Boyle (2014)	√	Interview & Observn	√	√	2nd Anal	√	2nd Anal	√	√	Extend √
6	Cahill & Diaz-Ponce (2011)	X	Interviewing	X	Inc ad d	Mod	√	√	Moderate	Mod	√
7	Campo & Chaudhury (2011)	√	Ethnography	√	√	√	√	√	√	√	Old refs √
8	Canning, Gaetz, & Blakeborough (2020)	√	Ethnography	√	√	2nd Anal	√	√	√	√	√
9	Carr et al (2011)	√	Phenomen.	mod	√	√	√	√	√	Mod	√
10	Clare, A et al (2020)	√	√	mod	PwAD	Exist.data	?	√	Elaborate	√	√
11	Dassa & Amir (2014)	√	Participatory	√	Mid -late	√	Interven	√	√	√	√
12	Eggers et al (2013)	X	Interview	X	Not ad d	8yrsapart	Mod	√	Moderate	Mod	Small √

13	Eisenmann et al (2016)	mod	Grounded theory	√	1 person	√	Mod	√	√	Mod	√
14	Ellis & Astell (2011/7)	√	Baseline> Intervention	√	1 > 5 pple	Staged	Intervn	X	Response	√	√
15	Ericsson et al (2011)	√	Grounded theory	√	√	√	Interven	√	√	√	√
16	Fels & Astell (2011)	√	Ethnology	√	6 - ad d	Conversn	Intervn	X	X	√	√
17	Fukui et al (2011)	√	X	√	add	Mod	?	X	X	√	√
18	Gjernes & Maseide (2020)	√	Video Ethnography?	√	Inc ad dem	√	√	√	√	√	Small √
19	Godwin & Poland (2015)	√	Phenomen.	mod	√	X	X	√	√	√	√
20	Helleberg & Hauge (2014)	√	Interview	√	9 Nurses	√	√	√	√	√	Small √
21	Hyden (2011b)	√	Video Ethnography?	√	1 person	X	mod	√	√	√	√
22	Kontos et al (2017)	X	Ethnography	√	dem	√	Interven	√	√	√	√
23	Kontos (2011)	X	Ethnography	√	13	Exist.data	√			√	√
24	Mok & Muller (2014)	√	Conversation Analysis	√	pwd	Observn	√	√	√	√	√
25	Moos (2011)	√	Exploratory	X	3 ad d	Exist.data	Interven	X	X	Mod	√
26	Nicholls et al (2013)	√	Focus groups	√	Carers	Exist.data	X	√	√	√	√
27	Norberg et al (2017)	X	Ethnography	X	ad d- 9	√	X	X	√	√	√
28	Palmer (2013)	X	Phenomen.	√	Carers	√	X	X	√	√	√
29	Peisah et al (2011)	X	Case Study	√	1 person	Observn	Interven	X	X	X	√
30	Perkins et al (2015)	X	Interview	√	Unit	√	X	√	√	√	√

31	Pöllänen & Hirsimäki (2014)	√	Phenomen.	?	3 people	Observn	Interven	√	√	√	√
32	Quinn et al (2014)	√	Focus Gps	√	11 family 12 carers	Discussion	√	√	√	√	√
33	Saunders et al (2011)	√	Ethnography	√	ad d	31	mod	X	√	√√	√
34	Schmidt et al (2017)	√	Grounded Theory	√	ad d	Observn & interview	mod	limited	√	√	√
35	Shibazaki & Marshall (2017)	√	Ethnography	Interview Obsern	Range	Inc Ad d	Intervn	√	√	√	√
36	Vigliotti, Chinchilli & George (2018)	√	Mixed	√	Various d	√	Interven	small	√	√	√
37	Walsmley & McCormack (2017)	√	Phenomen.	√	ad d	mod	mod	√	Moderate	√build on	√
38	Ward, Campbell & Keady (2016)	√	Ethnography Video	√	Not ad d	√	√	√	√	√	√
39	Watson (2019)	√	Ethnography	√	ad d	√	Interven	√	√	√	√
40	Wynn & Khayum (2015)	√	Case study	√	1 person	√	Interven	X	Moderate	√	√

APPENDIX 2 SUMMARY LITERATURE REVIEW OF FINAL RESEARCH ARTICLES (CHAPTER 3)

Author(s), (Year) and location	Aim	Sample size and Sampling	Methodology and Methods	Major findings and Limitations
1. Allison, Balbino, & Covinsky (2019) United States of America	To examine the ways in which a nursing home special care unit for people with ad dem functioned as family.	175 hours over 2 years, with residents, carers, and families.	Qualitative ethnographic study Observations and In-depth interview	Carers using verbal and non-verbal techniques relationships modelled on family. Interventions e.g. reminiscence. Explanation by carers, and attentiveness to non-verbal language through music, pets and sensory stimulation and engagement with each person with eye contact, laughter and even tears.
2. Batra et al. (2016) United States of America	To understand the preserved elements of self-identity in persons with moderate-severe Alzheimer's dementia.	7 people with Alzheimers dementia and 7 without dementia	Qualitative interviews of people	"Treating them as persons rather than persons with AD." Questions prompted dialogue related to self-identity in conversational style. Participants showed self-reference, understanding of their role in relationships and preferences. Findings suggest memory loss and other cognitive deficits not necessarily lead to loss of ''self.'' Training of care givers needed.
3. Berendonk & Caine (2016) Germany	To explore care staff understandings of life work (LSW) with residents with dementia	Convenience and theoretical sampling 36 care staff, 6 RACHs	Qualitative Grounded Theory Interviews and group discussions	Care staff recognized LSW value. 2 paradigms: 1. Staff gathering "true" past accounts about the person, esp. from relatives; 2. Staff being with the resident in relationship to support their continuing sense of meaning and well-being, through their life story, expressing their embodied identity and "narrative". Study affirms the 2nd paradigm.
4. Bourbonnais & Duchame (2015)	To describe the social positioning of older people living with AD	7 triads each with a person who screams	Secondary data analysis and triangulation of a critical	People capable of positioning in relational patterns: recognising their family caregiver, communicating, and repositioning themselves. Family and formal caregivers

Canada	who scream in a long-term care home.	with mod to severe dementia, family, and formal carers	ethnographic study	also position older people who scream. Person has capacities and tries to transform interactions using e.g. screaming, strongly demonstrative behaviour. Intervention to focus on strengths and healthy relations to enhance quality of care. But this intervention usually considered anti-social may receive staff push-back.
5. Boyle (2014) England, UK	To identify that people with advanced dementia who lack decision-making capacity can exercise agency creatively.	5 people with impaired speech	Conversational type interviews and using sensory aids to communicate	People assumed to lack agency; they are able to initiate social action or influence their personal circumstances. Their behaviour and emotion may be indicative of agency, e.g. particularly in response to the structural constraints. People with limited speech in relationship have non-verbal communication. They used creative, embodied, emotional forms of social action re their self-identity and agency.
6. Cahill & Diaz-Ponce (2011) Ireland	To ascertain similarities or differences in lived experience of quality of life (QoL) amongst nursing home residents with different levels of cognitive impairment	Purposive sampling 61 residents varying dem 28 ad d, not inc 5 non-verbal	Qualitative study In-depth interviewing	Residents with advanced dementia expressed their lived experience and agency in their needs and preferences. They expressed their need for social contact and “home”, and their loneliness and social isolation. Highlighted the need of people with advanced dementia for social inclusion. May have been experiencing depression, apathy or anxiety affecting their responses.
7. Campo & Chaudhury (2011) Canada	To examine social and environmental factors that facilitate interaction between residents in special dementia care units	Convenience sampling 44 residents and 5 staff members in special care units of 2 RACHs	Qualitative Ethnographic study Observing residents and interviewing staff	The study identified a number of factors that facilitate interaction between residents, including staff’s desire to initiate and participate in interaction and conversations, the gathering of residents in informal small groups promoting interaction through their day, carefully arranged various spaces that are cosy, close and comfortable with positioned seating and decoration for residents to relate to one another.
8. Canning, Gaetz, &	To explore the	7 girls aged	Ethnography of observations, field	Dance movement therapy and social interaction discerned changes in the children’s attitudes to positive attitudes and

Blakeborough, (2020) Canada	development of relationships between school-aged children and older adults with dementia in RACH.	7-9 in ballet classes with people with mod to ad dementia for six mths	notes, and pre and post interviews of children	the forming of significant relationships. Rather than diminished engagement in activities, people engaged in building relationships and meaningful activity. This engagement to build relationships is beneficial and dispels negative stereotypes.
9. Carr et al. (2011) Canada	To explore meaning of spiritual care for patients with moderate to advanced dementia in an acute care unit	Purposive sampling- 29, inc. 8 with ad d, their families, RNs, and chaplains	Qualitative Phenomenological study	People appreciate the little things, those acts of warmth, developing relationships of depth, kindness and support, and opportunities to give and receive. Some participants indicated the importance of the respect of others for their individual identity and preferences such as religious needs. Limitations: The researchers do not make it clear how the participants with advanced dementia expressed these views. Various forms of spiritual care described.
10. Clare, A et al (2020) England, UK	To develop an understanding of how people with late-stage dementia may express themselves nonverbally and interact with others during a live music group over time.	8 people with ad dem, 4 carers, 3 musicians in 8 hr-long weekly live music	Visual grounded theory used to analyse video data	Live music group facilitated a multisensory communicative environment allowing for verbal and non-verbal communicative actions, social interaction and agency to develop over time. Due to time, one-to-one interaction within a group setting and the music characteristics. Helped develop mirroring, turn-taking, humour, and increased nonverbal communication and a connection between people. Reduced isolation, facilitated agency, by affirmation and relationships.
11. Dassa & Amir (2014) Israel	To explore how the activity of singing familiar songs facilitates conversation	Purposive sampling of 6 residents with moderate to advanced dementia	Qualitative Participation in sessions recorded and transcribed Intervention	Songs from people's past encouraged reminiscing. Group singing led to interaction and comments, and feelings of being together, and the expressing of emotions, mostly positive of enjoyment, but also at times some sadness. Limitations: This study focuses on conversations and not more general non-verbal interactions between residents and others.

12. Eggers et al. (2015) Sweden	To explore the ways nurses understand the communication of residents with advanced dementia	Purposive sampling 6 nurses, also interviewed 8 years prior	Qualitative content analysis of interviews	When the nurse understands persons with advanced dementia as being able to communicate, they are open to relationships with them. Give nurses understanding of each person, their past, their needs and their ways of communicating. Consequently, the nurses' role is to facilitate interaction by being available, giving time, listening, and opportunity to the person to communicate however they are able in the present.
13. Eisenmann et al. (2016) Germany	To describe with an illustrative example the expression and perception of needs of people with advanced dementia with limited communication	Purposive sampling, 1 person from a larger study	Qualitative Grounded Theory to analysing data from the larger study represented by this case study	Emphasis on carers prior relationships with person, along with sensitive attentive careful listening. During his end-of-life phase in palliative care, the resident was able to respond to simple questions to express his needs, preferences and concerns regarding his care, for example, reacting to noise. Limitations: This study did not elucidate any last will and testament content in the conversation.
14. Ellis & Astell (2018) Scotland, UK	To describe Adaptive Interaction, an intervention facilitating communication and interaction with one person with advanced dementia	Purposive sampling 1 resident	Qualitative interventionist ethnography Intervention	Relationship developed along with specific techniques to open up verbal and non-verbal interaction. The person considered to have no communication capacity responded to mirroring of their tone, pace and gesturing. Person displayed a diverse non-verbal repertoire, using sounds and gestures and the capacity to initiate, imitate, take turns and sustain interaction over an extended period. the person can engage in interaction. Limitations: Small pilot.
15. Ericsson et al. (2011) Sweden	To describe how relationships are formed with people with moderate to advanced dementia	Purposive sampling, 9 residents In 6 RACHs	Qualitative Constructivist Grounded Theory Intervention Videos of interactions, followed by interviews of video participants	Intervention "Relational Time" provided residents and staff opportunities to grow in their relationships to build trust and reciprocity through time spent together. The focus of RT is on the person's capacity to communicate and express their needs, preferences and interests. The person needs to learn trust that the other will spend time with them.

16. Fels & Astell (2011) Canada UK	To explore how the use of familiar props e.g. photos promotes reminiscence and story-telling in people with ad dementia	Purposive sampling, 13 residents In a RACH	Qualitative Intervention Part. Observn. Reminiscence	Some people with advanced dementia are still able to engage with photos and tell stories about them, according to their capability. Most told at least one story. There were four components of each personal narrative: a story text, the story-telling context, the listener as a collaborative supporter, their attention of the listener, and encouragement of family and staff.
17. Fukui et al. (2011) Japan	To develop a process to identify needs behind BPSD and desire to return home using a team approach; and to apply the results to educate new workers	Purposive sampling 12 staff caring for residents with ad dementia	Qualitative Group Process similar to Action Research Intervention	Participants developed consistent caring ways of responding to people's repeatedly desire to return home. The intervention identified 5 steps to assist the resident to settle and be at home: Listening and sensitive mirroring, seeking to understand their inner feelings, examine the issues in the immediate context, reflect on the person's key word at this time.
18. Gjernes & Maseide (2020) Norway	To explore how Residents, some "with verbal and cognitive incapacities" in RACH were given the opportunity to act as ordinary persons and maintain ordinariness	Residents with dementia, kitchen assistant nurses or caregivers	Ethnomethodological and other pragmatist approaches: Interviews and observations	Social and moral norm of ordinariness: social and situated practices, social participation, agency and contribution was central for care by regularly involving people in everyday tasks. This activity is facilitated by "caregivers" helping people to retain their identities and dignity, encouraging relational citizenship, capabilities and capacities, doing things that are meaningful and enjoyable, rather than deficit and decline.
19. Godwin & Poland (2015) England, UK	To explore the expression of self of people with moderate to advanced dementia	Purposive sampling 10 people in 3 RACHs	Qualitative Mixed methods with Interpretative Phenomenological Analysis of semi-structured interviews and supportive information of family	Residents continued to experience well-being, a sense of self, moral responses consistent with their personality, and capacity to express their emotionality. Their well-being was facilitated by their sense of belonging, agency, choices and activity, being affirmed and respected by others and feeling safe within the home. Some residents experienced ongoing ill-being consistent with their previous negative life experiences. Some expressed awareness of experiencing decline.

20. Helleberg & Hauge (2014) Norway	To ascertain carers and nurses views about what constitutes high quality care of people with advanced dem.	Purposive sampling 9 nurses and carers in 2 RACHs	Qualitative Interviewing staff	Quality care like a dance. Best praxis was considered to be synchronized to the needs, preferences and past of the person, modified to the resident's tempo and mode of being at the time, and taking the lead to change the person's behaviour. Some staff recognised to be attuned to the person they needed to be respectful and not rushed, and attentive to the person's interactions.
21. Hydén (2011b) Sweden	To explore how the person with advanced dementia makes noises in response to interactive occasions, and the meanings for others	Part of a larger study Case study of 1 person	Qualitative Videoing interaction of residents	When resident's "noise making" is contextualized it is a part of the interaction, as their contribution or response with others. Other residents respond to these sounds as being meaningful participations in the communication event, e.g. sitting at the table sharing a meal together. Counters the attitude that noises may be incidental on the part of the person, irrelevant or interruptive of others.
22. Kontos et al. (2017) Canada	To understand the responses of people with moderate to advanced dementia to a regular visit of clowns	Purposive sampling 24 residents, 4 clowns	Qualitative Ethnographic study Intervention Observing and interviewing residents, clowns	Residents and clowns in reciprocal, interactive relationships wherein residents responded to and initiated interactions with the clowns. Residents expressed, through sounds, words and embodied non-verbal language, their responses of imaginative playfulness, humour and connection with the clowns.
23. Kontos (2011) Canada	To explore the embodied expressions of self of people with moderate to advanced dementia	Originally purposive sampling 13 residents, using earlier study	Qualitative Ethnographic study Observing residents and interviewing	Residents embodied expressions communicate socially with one another. Such non-verbal expressions needed to be understood in context. They included physical gestures and movements, facial expressions, and interactive habits, such as touch, and rituals. Courtesies, empathy and sharing of feelings were expressed in embodied ways. Socially connecting with others was demonstrated to be a significant and continuing aspect of residents' lives.

24. Mok & Muller (2014) Australia & United States of America	To examine how conversations function between people with various stages of dementia	Residents with mild to advanced dementia in RAC	Exploratory qualitative observations of Conversations in natural setting Interactive options for the construction of dialogue	Relationships between people can be positive but also turn to being misconstrued. People are often able to perform the various patterns of interaction, e.g. turn taking, expressing reciprocal interest in one another, and some engage for a considerable length of time (up to an hour). When interactions do not go well there must be facilitation of safe and deliberate egress. Casual conversations are a meaningful activity, and a strength.
25. Moos (2011) Austria	To explore the communicative competence of people with moderate to advanced dementia in humour, irony and sarcasm	Originally purposive sampling, using earlier study, 3 residents from 1 RACH	Exploratory qualitative Conversations in natural setting Intervention	Naturalistic conversation of each person using humour, sarcasm and irony in their interactions with other residents and staff. These rhetorical interactive devices continue to be preserved and expressed in interactions. They express their identity and agency in creative and interactive ways with others, that are favoured modes of relating in people of all circumstances.
26. Nicholls et al. (2013) Australia	To explore the benefits of touch as part of Namaste intervention for people with advanced dementia to improve palliative care	Purposive sampling of 31 carers in 3 RACHs	Qualitative Focus groups	Carers used touch and found to encourage interconnectedness and reciprocal relationships. As a means of showing regard, care and respect, and meaning and pleasurable effect. The person communicates their well-being with smiling, relaxed posture and body, appreciation, indicating their agency and identity.
27. Norberg et al. (2017) Sweden	To explore moments of homecoming for residents with advanced dementia	Purposive sampling 9 residents in 1 RACH	Qualitative Ethnographic study Observing residents and interviewing	Residents express feelings of being at home at times, and at other times feelings of not being at home. Relational connectedness, meaningful activity and a cosy, homely environment precipitate a sense of being at home within the person so they are able to communicate being settled and content in the non-verbal and verbal language.
28. Palmer (2013) United States of America	To explore the perspectives of family care givers about what constitutes person-	Convenience sampling 15 family members in	Qualitative Phenomenological Analysis of semi-structured interviews	Family care givers being regularly present with their relative in relationship and conversation, to advocate for their past story, needs, and preferences, and supplement the care of staff. They prevent the person experiencing a

	centred care for people with moderate to advanced dementia	several RACHs		"social death". They noted staff members who continued to provide person-centred care, e.g. calling the person by name and interacting with them, and other staff who did not respect the person.
29. Peisah et al. (2011) Australia	To explore the benefits of art therapy to improve palliative care for person with ad dem	Purposive sampling 1 resident in 1 RACH	Qualitative Case Study Intervention	The activity was specific to the person's interests, needs, strengths and wish to participate. The resident formed a relationship with the art therapist, interacting, reminiscing and able to use her preserved skills. Limitations: The data set small.
30. Perkins et al. (2015) New Zealand	To explore the spirituality of people with advanced dementia	Purposive sampling 42 residents, families & staff in 2 memory support units in 1 RACH	Qualitative semi-structured interviews	Preservation of each person's self and spirituality and identity supported by reciprocal relationships with family, other residents and staff. Their identity was preserved with humour, being surrounded by their favourite possessions, meaningful activities including music and dance, nature, and continuing religious practices where relevant.
31. Pöllänen & Hirsimäki (2014) Finland	To explore the benefits of craft activities for people with advanced dementia	Purposive sampling 3 residents in 1 RACH	Qualitative Phenomenology Case Study Intervention	Activity specific to the person's interests, needs, strengths and desire to participate. They engaged with reminiscing and reciprocating non-verbally and formed a relationship with the facilitator, interacting with many more words and sentences showing preserved skills.
32. Quinn et al. (2014) Wales, UK	To explore how family members perceive awareness of their relative with mod to ad dem	Purposive sampling 11 family, 13 staff	Qualitative Focus groups	Awareness of person to respond to factors in the environment. Interpretations of family dependent on their close connection with person, and for staff dependent on providing care and connecting with the person. Awareness varies. Person's continuing sense of identity; see it in his eyes; learning to read them.

33. Saunders et al. (2011) United States of America	To explore how people with advanced dementia form relationships	Purposive sampling 31 residents and 10 staff in 1 RACH	Qualitative Ethnographic study Observing residents and interviewing	People are able to interact with each other and form relationships using communication common in interaction. As residents are seated together and participate in activities they connect, make comment and appreciate companionship. Limitations: The study did not consider staff interactions with residents as another facet of relationships.
34. Schmidt et al. (2018) Germany	To explore needs of people with ad dem and how to meet those needs. Not directly include people with ad d due to lack of commn abilities- verbal/ non-verbal language	6 RACHs 42 staff 14 family 30 residents observed	Qualitative Grounded Theory Part. Observation Interview Group Discussion	Data analysis generated 25 physical, psychosocial, and spiritual needs divided into 10 categories. Physical needs: “food intake,” “physical well-being,” and “physical activity and recovery.” Psychosocial needs: “adaptation of stimuli,” “communication,” “personal attention,” “participation,” “familiarity and safety,” “self-determination.” Spiritual needs addressed “religion.” The results revealed the importance of personhood.
35. Shibazaki & Marshall (2017) Japan and England, UK	To explore the effect of attending Concerts in the RACH in promoting well-being for people with dementia including in the advanced stage	22 concerts in RACH	Qualitative Observations of residents and interviews with staff and family	Concerts beneficial to all clients and nursing staff. Those with advanced dementia exhibited decreased agitation and anti-social behaviour. Staff reported increased care and cooperation. Family members noted increased well-being in their partner/parent as well as in themselves. Knowledge of music and preferences remain when other cognitive skills and abilities have disappeared.
36. Vigliotti, Chinchilli, & George (2019) United States of America	To evaluate benefits of TimeSlips, a group creative telling intervention, focused on quality of life, interactions and resident–caregiver relationships	22 residents with mild to severe dementia Weekly for 6 month period	Mixed methods Observations, testing QOL, and Analyses Using only the qualitative findings	Benefits of “TimeSlips” for persons at all levels of dementia severity. Bonding and interactions between participants were across all levels of severity. For example, one participant with severe dementia smiled and “babbled” in response to her neighbour’s comments. Other participants with severe dementia would share their “TimeSlips” picture with neighbours. Reminiscence and laughter prevalent.

37. Walsmley & McCormack (2017) Australia	To explore preserved awareness and capacity for non-verbal communication in people with advanced dementia	Purposive sampling 5 residents and their families in 1 RACH	Qualitative Phenomenological Analysis of videoed interactions	The person retains awareness and capacity to engage with family. “Out of step” interactions characterised as “social frustration”, non- reciprocity, and overlooking the person with dementia in the interaction. Family need to accept and adjust to the person’s modified communication. ‘In-step’ interactions included creative sensory stimuli, humour, play, and reciprocation non-verbal language.
38. Ward, Campbell & Keady (2016) England, UK	To focus upon hair care and styling in context of a wider consideration of appearance, how it is managed and what it means for people living with dementia. Not directly applied to people with advanced dementia but relevant	8 different care-based hair salons; 23 people with dementia (16 women and 7 men)	Qualitative study akin to ethnography Mapping of use of service, In depth interviews with all stakeholders, Filming over 10 months	The ways agency is exercised by women with dementia, in relationships and interactions together and with hairdressers facilitating their interaction capabilities. There is a link between inter-personal practices of appearance and wider social conditions provoking social resilience and resistance in space and bodies in dementia care. Women with ad d retain desire to promote agency through their appearance, and expression of ongoing capability and capacity to become. Debunks stereotypes of fourth age.
39. Watson (2019) Scotland, UK	To examine the ways in which embodied selfhood affects communication and care provision to people with ad dem	Purposive sampling 40 residents and 33 staff in 1 RACH	Qualitative - Existing data from PhD thesis. Ethnography Observing residents and interviewing staff Intervention as a care worker	The embodied ways residents communicate and maintain their agency in routines and activities. Familiarity and relationships formed with regular staff with knowledge about individual residents’ needs, preferences and past is important. Revealed the person’s preservation of self, need for affirmation in experiences, and being responded to when distressed. Evidence of the inter-bodied and reciprocal nature of relationships.

40. Wynn & Khayum (2015) United States of America	To examine a speech therapy intervention with 1 person with advanced dementia to assist their interaction	Purposive sampling 1 resident in 1 RACH	Qualitative-Case Study Intervention	Model of support for person’s strengths, a unique approach to speech therapist’s role. Intervention included carers facilitating person’s communication, simplifying theirs, assisting sensory challenges, encouraging interactive activities, giving choice to support their agency.

APPENDIX 3 ETHICS FINAL APPROVAL NOTICE

Project No.:	**7552**
Project Title:	The Voice of the Older Person with advanced dementia in residential aged care (RAC): What does it mean for a resident to have their voice in RAC?
Principal Researcher:	Pastor Julie Simpson
Email:	simp0195@flinders.edu.au

Approval Date:	24 August 2017	Ethics Approval Expiry Date:	**30 September 2021**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioral Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or emailhuman.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **24 August** (approval anniversary date) for the duration of the ethics approval using the report template available from the Managing Your Ethics Approval SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **24 August 2018** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, changes);
- changes to research protocol;
- changes to participant recruitment methods;
- changes of procedures used to seek informed consent;
- changes / additions to information and/or documentation to potential participants;
- changes to research tools
- extensions of time.

To notify the Committee of any proposed modifications to the project please complete and submit the *Modification Request Form* which is available from the Managing Your Ethics Approval SBREC web page.Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 orhuman.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Rae

Mrs Andrea Fiegert and Ms Rae Tyler
Ethics Officers and Executive Officer, Social and Behavioural Research Ethics Committee
Andrea - Telephone: +61 8 8201-3116 | Monday, Tuesday and Wednesday
Rae – Telephone: +61 8 8201-7938 | Tuesday, Thursday and Friday

Email: human.researchethics@flinders.edu.au
Web: Social and Behavioural Research Ethics Committee (SBREC)

Manager, Research Ethics and Integrity – Dr Peter Wigley
Telephone: +61 8 8201-5466 | email: peter.wigley@flinders.edu.au
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042 GPO Box 2100 | Adelaide SA 5001

APPENDIX 4 ETHICS MODIFICATION REQUEST

For projects previously approved by the SBREC

A Modification Request should be submitted for all items listed below:	IMPORTANT
1. proposed changes to the research protocol; 2. proposed changes to participant recruitment methods; 3. amendments to participant documentation and/or research tools' 4. change of project title; 5. extension of the ethics approval expiry date / extension of time; and 6. personnel changes (e.g., additions, removals, supervisor changes) Submit modification requests to human.researchethics@flinders.edu.au Typically, the Committee's response will be emailed to you in 1-2 weeks.	a) Proposed modifications should *not* proceed until formal notification of modification approval has been received. b) Annual reports - annual progress reports should be up to date *before* a modification request is submitted. c) Indigenous peoples – modifications that involve or impact on Indigenous peoples in Australia will also be reviewed by the Flinders University Office of Indigenous Strategy and Engagement (OISE), which will impact Committee response time. d) Contact Details – email SBREC if details change as Ethics *is not* linked to Student Two or Human Resources.

1. Project Information

Project No.	**7552**	Ethics Approval **Expiry Date**	30th Sept, 2021
Project Title	The Voice of the Older Person with advanced dementia in residential aged care (RAC): What does it mean for a resident to have their voice in RAC?		
Principal Researcher	Associate Professor Ruth Walker	Email address:	simp0195@flinders.edu.au
Annual Reports up to date?	No	Next annual report due?	24th August, 2021

2. Extension of time

2A Extension of Time Requested (if applicable)

Current Ethics Approval Expiry Date	N/A	New Expiry Date requested	

2B Justification

3. Change of Project Title

3A Change of Project Title (if applicable)

Old project title: N/A

New project title:

3B Participant Document Revisions

Please note: if the project title is changed, copies of all documents to be distributed to potential participants will need to be revised to include the new title (e.g., email text, Letter of introduction, Information Sheet, Consent Form). Please submit copies of the revised documents for review.

Revised Participant Documents Attached?

4. Change of Personnel

4A Change of Personnel Summary (if applicable)

Add/ remove	Full name & title	Postal address	Email address
Remove	Associate Professor Ann Harrington, Principal supervisor has resigned		ann.harrington@flinders.edu.au
Add	Associate Professor Ruth Walker, has now become Principal Supervisor	GPO Box 2100 Adelaide SA 5001	ruth.walker@flinders.edu.au

4B Conflicts of Interest

Comment on whether a conflict of interest may exist for any new personnel (e.g., role / relation to participant source). If yes, explain how this will be managed.

No conflict of interest has been identified.

4C Participant Document Revisions

Please note that if personnel are added and/or removed from a project that documents to be distributed to potential participants will need to be revised to ensure that a current list of researchers is included (e.g., email text, Letter of Introduction, Information Sheet, Consent Form).

Revised Participant Documents Attached? N/A

Fieldwork has now concluded so no further distribution of materials will occur.

5. Modified Research Protocol

5A Revision of Research Protocol Table

Please indicate in table below what type of changes are proposed.

Select Options that Apply	
Research Objectives Revision, or addition to, research objectives (item D1c)	**N/A**
Research Method – Revision of approved research method – Addition to approved research method	**N/A**
Research Participants – Addition of new participant group – Exclusion of participant group already approved by Committee	**N/A**
Consent – Revised method for seeking informed consent from participants – New method for seeking consent	**N/A**
Recruitment Process Change to approved process for participant recruitment	**N/A**
Research Tools For example, survey, interview questions, focus group discussion topics. – Revision of approved research tools	**N/A**

Important Note

If you would like to recruit any participants from any organisation that falls under the banner of the Southern Adelaide Local Health Network (SALHN); such as Flinders Medical Centre or Noarlunga Hospital; the committee advises that ethics approval will need to be sought from the Southern Adelaide Clinical Human Research Ethics Committee (SAC HREC) instead of this committee.

Select Options that Apply	
– New research tools	
Documents / Information For example, verbal script, email text, Letter of Introduction, Information Sheet, Consent Form – Revision of existing documents / information – New documents / information	
Other (if yes, please specify)	

Extension of time spent with some participating residents on some occasions-
Revision of information given verbally

5B Outline of Research Protocol Changes
Provide a clear outline of changes and/or additions to the research protocol are being requested and explain why it is necessary to address the research objectives (e.g, change to research objectives; changes to recruitment process; change to research tools; addition of research tools etc).

During the daily course of the fieldwork some of the participating residents chose to spend a longer time with me than maximum of 20 minutes set by the HREC Committee in my original application. An extension of time spent together was initiated by the participating resident him or herself, either by their wanting to continue to be with me or seeking to extend their time with me by asking this of me. When I made the decision to remain with them it was on the basis of the Process Consent method outlined in the original ethics application. When a person wished to extend our time together, I used this method of consent, assessing whether the person was in a state of well-being; and was not indicating tiredness or distress according to their verbal and non-verbal indicators. These indicators for each participating resident had been previously recognized and recorded in the establishment of my research relationship with each of them.

Informed consent was given by the substitute decision makers to my spending pleasurable time with their relative within parameters that had been identified as being within their relative’s capacities. Process consent measures with each participating resident gave no indication of ill-being at any time during their involvement in interactions with myself as the researcher.

5C Participant Document Revisions
To ensure that informed consent can be obtained changes to the research protocol may need to be reflected in the documents to be distributed to potential participants.(e.g., email text, Letter of Introduction, Information Sheet, Consent Form). Revised documents and/or new participant documents may need to be provided for review.

Revised Participant Documents Attached?	No

6. Permissions / Other Ethics Committee Approvals

Please indicate whether any other ethics committee approvals and/or permissions need to be sought that are related to the requested modification. If yes, please either (a) provide a copy of approvals and/or permissions **OR** (b) confirm that copies will be submitted to the committee on receipt.

7. Aboriginal and/or Torres Strait Islander peoples

7A Impact and/or involvement of Indigenous peoples
Please indicate whether the *proposed modification* will involve or impact on Australian Indigenous peoples.

YES	
NO	√

7B Explanation
IF the proposed modification involves or impacts on Australian Indigenous peoples, please explain how.

APPENDIX 5 LETTER OF INTRODUCTION FAMILY MEMBERS-SUBSTITUTE DECISION MAKERS

Associate Professor in Nursing Care of the Older Person **Ann Harrington,**

School of Nursing and Midwifery

Sturt West Wing (W408)

Sturt Buildings

GPO Box 2100
Adelaide SA 5001

Tel: 082013483
Fax: + 61 8 82761602
ann.harrington@flinders.edu.au

http://www.flinders.edu.au
CRICOS Provider No. 00114A

September, 2017

LETTER OF INTRODUCTION
Family Members-Substitute Decision Makers

Dear Family Member,

This letter is to introduce Julie Simpson who is a PhD student in the School of Nursing at Flinders University. She will produce her student card, which carries a photograph, as proof of identity. She is undertaking research leading to the production of a thesis and other publications on the subject of

> **The Voice of the Older Person with advanced dementia in residential aged care (RAC): How does an older person express their voice in RAC?**

As the substitute decision maker for ………………………………….your consent is sought for him/her to participate in this research project.

Julie Simpson's research project will explore:

1) With residents with advanced dementia themselves, how they express their voice verbally and non-verbally, and what this means to them;
2) And with staff members and family members, what are current and any new practices for promoting the voice of older people with advanced dementia in residential aged care.

Julie would like to invite you to assist with this project in the following ways:

1) By giving your consent as a substitute decision maker for …………………for her/him to participate. This would include participating in conversations and/or interactions with Julie which would be audio taped; being observed by Julie in individual and group activities (apart from personal and hygiene care); and photographing the resident in interactions. The audio tapes, and photographs of the resident would only be undertaken with your and the resident's consent. These will then only utilized in the interviews and in the analysis as part of the research project.

   Julie asks that you sign the following Substitute Decision Maker Consent Form if you consent to …………participating. Please note that an understanding of the resident's well-being will be obtained from you and staff members. Residents will only be approached when they are in a state of well-being.

2) You, or your delegated family member, or special friend of ………………………may also agree to being interviewed about how your resident expresses their voice.

   Julie asks that you sign the Informed Consent Form if you wish to participate in the research project yourself.

Since all involvement in this research project will occur in [redacted] the anonymity of participants cannot be guaranteed. However, be assured that any information provided will be treated in the strictest confidence. The specific content of the interviews will remain confidential. None of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Your signed consent, on one or both of the attached forms, will allow Julie to use the recordings or transcriptions in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. It may be necessary to make the recording available to secretarial assistants (or a transcription service) for transcription, in which case you may be assured that such persons will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8 8201 3483, fax 8 8276 1602 or e-mail ann.harrington@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

Associate Professor in Nursing Care of the Older Person Ann Harrington RN PhD FACN
School of Nursing & Midwifery
Flinders University,
GPO Box 2100
ADELAIDE SA 5001 AUSTRALIA

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7552). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

APPENDIX 6 INFORMATION BROCHURE FOR RESIDENTS’ SUBSTITUTE DECISION MAKERS AND FAMILY MEMBERS/FRIENDS AND REPLY PAGE

What are the ethical guidelines for the research project?

As a PhD student Julie has had to submit to a rigorous ethics process to gain permission to undertake the research project. An ethic of care approach will be the underlying principle “to act out of care and compassion in ways that benefit the residents, care staff, and the organization that are part of my research”. The priority is person and relational-centred care.

How will I receive feedback?

Julie will provide feedback to those participants who have been involved in the research project. This may include a brief or summarized account of the findings from the final Report, and/or a verbal statement of this summary. Outcomes from the project will be written up and presented as a final report to [redacted] by Julie as the researcher.

What will be benefit from participating in this study?

No participant in the research will receive any payment, or inducement to be involved. However, a number of research studies, involving older people in aged care homes, have identified how much they have valued making a contribution, and that this enhances their sense of well-being.

How the voices of older people with advanced conditions of dementia occur, including through the relationships with, and the practices of, staff members and family members/close friends, will be explored. Therefore, this research has implications for assisting in the planning and delivery of services to individual older people, practices in aged care homes, and the residential aged care sector.

INFORMATION BROCHURE FOR RESIDENTS’ SUBSITUTE DECISION MAKERS AND FAMILY MEMBERS/FRIENDS

[redacted]

DATE

INTRODUCTION OF RESEARCH PROJECT

To be undertaken by Julie Simpson,
PhD Student, Flinders University

August - November 2017
January – April 2018

Thank you for taking time to read this information brochure, and responding if you wish to participate

Introduction

Julie Simpson is a 2nd year PhD Student in the College of Nursing and Health Sciences at Flinders University. Permission has been granted by [redacted] for Julie to undertake her PhD research project at two of its sites.

The title of her research:

The Voice of the Elder in Residential Aged Care: How does a resident express their voice in RAC? How is their voice supported by the care team?

Research Supervisors

Julie is supported by a number of supervisors in three ways:

1.Flinders University: Principal supervisor Associate Professor Ann Harrington, College of Nursing & Health Sciences, Ph 8201 3483 if you have any queries or concerns regarding the research project; Adjunct Supervisors: Dr Aileen Collier, and Rev Dr Alan Niven

2. [redacted]

[redacted]

What is the purpose of the project?

This research project aims to engage older people with advanced conditions of dementia, in its various types, who reside in the dementia houses, and those people who care for them as staff and family/friends. Only those who have given their consent will be involved.

The objectives of the project are to explore in residential aged care:

- How older people with advanced dementia, enact and express their voice in residential aged care;
- What are the meanings older people, with advanced dementia, give to having voice in residential aged care;
- To explore current practices and how the culture in residential aged care affects an older person's voice;
- To consider exemplars of practices promoting the voices of older people with various types of advanced dementia.

How will the research project be undertaken?

The research project will be done in two interconnecting parts:

Part 1: "Shadowing" /spending time alongside a number of residents (up to 15)

- Auditory recording of a participating resident in conversation with myself for a moment, few minutes or up to 20 minutes depending on the resident's assent and capacity;
- Observation and notes by myself of residents in individual and group settings with other residents, staff and family;
- Interviews with staff members who care for a resident;
- Interviews with family members/close friends.

Part 2: Analysis of data collected from residents as we go along

- By myself
- With staff or family/friend interview (5-20 minutes), up to 3 times

What am I asked to do?

Julie invites you to assist with this project by consenting as the Substitute Decision Maker to the resident participating in this research project. The involvement of the resident will be with their initial assent indicated by them verbally or non-verbally to Julie. This will be followed by you giving your consent by reading, understanding, and signing the Substitute Decision Maker Consent Form, provided by Julie, if you wish for them to participate.

Furthermore, you are also invited to participate by being observed in your interactions with your individual resident; and/or being interviewed for no more than 5-20 minutes about how this resident expresses their voice, and what assists them to do this. Your participation will also be with your signed consent on the Informed Consent Form provided by Julie, and at your convenience.

In the interviews you may choose to refuse to answer any questions. The interviews, with your permission, will be recorded using a digital voice recorder to help with considering the results. Once recorded, the interview will be transcribed (typed-up) and stored in a password protected computer and server file, that only the researcher will have access to. You will be able to read any transcripts of the resident or yourself if you wish.

There is no obligation to participate. If you give consent to the resident or yourself participating, you are free to withdraw from participating in the research project at any time without disadvantage or penalty.

Will the resident or I be identifiable in this study?

As all involvement in the research project will take place in [redacted] setting anonymous participation is not guaranteed. However, all information given by participants to the researcher will remain confidential.

Only de-identified findings and recommendations will be made in the final thesis, report and publications.

Are there any risks if the resident or I am involved?

As the researcher, Julie anticipates few risks for your resident or yourself from involvement in this study. All participation will be sensitively managed. Please note that each resident will only be approached in a state of well-being and giving assent, in discussion with you and/or staff members.

Staff will be immediately contacted if a resident or family member participant experiences distress in an interview. Where a resident appears unsettled Julie will, personally or with the assistance of another staff member, seek to settle the resident. She will also courteously terminate the session with them. Their responses will be taken into account regarding future encounters.

At the end of each session Julie will assess the well-being of each resident. She will leave the resident(s) affirming that they have made a positive contribution. Before concluding the research project Julie will seek to manage her departure in sensitive ways. Julie will inform all participants of the finishing time. At the end a finishing event will be held by Julie for all participants.

REPLY PAGE (Separate A5 Insert)

(Substitute Decision Maker/Family Member)

How do I agree to participate?

Participation is voluntary, and your situation at [redacted] will not be affected in any way if you choose not to participate.

If you wish for the resident and/or yourself to participate please fill in the Reply Page, and return to the Sealed Box in Reception marked "Research" as soon as possible.

If you consent for the resident……………………….(name) to participate please fill in your contact details.

Name ………………………………………………………….

Contact details (Phone no.)……………………………….

Do you wish to also participate? (circle) Yes / No

Julie Simpson will contact you as soon as possible to answer any questions and to get your formal consent to participation.

REPLY PAGE (Separate A5 Insert)

(Substitute Decision Maker/Family Member)

How do I agree to participate?

Participation is voluntary, and your situation at [redacted] will not be affected in any way if you choose not to participate.

If you wish for the resident and/or yourself to participate please fill in the Reply Page, and return to the Sealed Box in Reception marked "Research" as soon as possible.

If you consent for the resident……………………….(name) to participate please fill in your contact details.

Name ………………………………………………………….

Contact details (Phone no.)………………………………

Do you wish to also participate? (circle)   Yes   /   No

Julie Simpson will contact you as soon as possible to answer any questions and to get your formal consent to participation.

APPENDIX 7 PROCESS CONSENT ASSESSMENT INSTRUMENT FOR EACH CENTRAL PARTICIPANT

Process Consent Assessment Instrument

Name of Resident…………………………………………

If, and then how, a resident chooses to participate in daily activities **Yes / No**

Sitting/Moving ……………………………………………………………………………..….

……………………………………………………………………………………………………

Specific Places / Activities………………………………………………………………….…

……………………………………………………………………………………………………

Indicators of Well-being	Indicators of Ill- Being	Triggers of decrease in their well-being	Behaviours: if resident has specific need

Date	Place	Descriptions of Responses by Person	Outcomes

APPENDIX 8 INFORMED CONSENT FORM SUBSTITUTE DECISION MAKER

PROXY CONSENT FORM

FOR PARTICIPATION OF RESIDENT IN RESEARCH

SUBSTITUTE DECISION MAKERS

(by interview, observation, auditory recording and/or group)

The Voice of the Older Person with advanced dementia in residential aged care (RAC): How does an older person express their voice in RAC?

I …..

being over the age of 18 years, and the substitute decision maker for

……………………………………………… hereby give proxy consent to their participation as requested in the Letter of Introduction/Information Brochure for the research project on "The Voice of the Elder in Residential Aged Care".

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to participation in the research project with audio recording of …………………….. in individual conversations and/or interactions with the researcher; and in individual and group activities with staff members and family members, not including activities of personal hygiene.
4. I am aware that I should retain a copy of the Information Brochure and Consent Form for future reference.
5. I understand that:

- Since …………………. participation in this research occurs in their residential setting, their anonymity will not be guaranteed.

- While the information gained in this study will be published as explained, …………………………………will not be identified, and individual information will remain confidential.

- The resident and/or I may not directly benefit from taking part in this research.
- ………………….is free to dissent to participating.
- I am free to ask that the recording/observation be stopped at any time.
- I am free to withdraw …………………… from the project at any time.

6. I understand that the well-being of the resident will remain the priority, and that:

- If I provide proxy consent for ………………. to participate I will have the opportunity to provide to the researcher indicators of when he/she is in a state of well-being and when he/she is discomforted.
- I recognize that the researcher will assess ……………………. according to these indicators so that they will also express their choice to participate or not.
- If ……………. indicates they do not wish to participate or that they wish to conclude the session then the researcher will courteously not commence or conclude the session with them. The researcher will ensure that, as appropriate, she or another staff /family member provides support so ……………… returns to a state of well-being.
- I may withdraw my proxy consent at any time from the session or the research without disadvantage. This will have no effect on any treatment or service that is being provided to my loved one (resident) or any supportive service to myself by [redacted].

Resident's Name……………………………………………………………….

Substitute Decision Maker's Name……………………………………………

Substitute Decision Maker's signature…………………………………Date……..

I agree to another family member/ friend, ………………………………being

involved in the research project so that their perspective may be given

regarding the ways …………………expresses their voice.

Resident's Name……………………………………………………………….

Substitute Decision Maker's Name……………………………………………

Substitute Decision Maker's signature…………………………………Date……..

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name………………………………………………………................

Researcher's signature…………………………………..Date……………………

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of the following clause, as appropriate.

To be signed below after collection of the data

I, the substitute decision maker for …………………………… have read a transcript of …………………….. participation, and agree to its use by the researcher as explained. My signature appears below,

Substitute Decision Maker's Name……………………………………………

Substitute Decision Maker's signature…………………………………Date……..

Please return to: Julie Simpson
Sealed Box in ……………………………………………….

APPENDIX 9 OBSERVATIONAL GRID FOR EACH CENTRAL PARTICIPANT

Setting	**Activity**	**Time of day**	**Length of activity**

Arrangement of seating (draw)

Pseudonym:

Well Being / Ill being Score (+5 to –5) :

Process Consent:

Making verbal comments and/or commentary

Watching and engaged

Disengaged, withdrawn

Interacting with others non-verbally in eg. Gesture

Interacting with others verbally

Expressing silence and ways this is expressed

Making coherent comments

Initiating

Asserting
Laughing
Joking, using humour
Reminiscing and life storying
Expressing ritualized behavior e.g. greeting, courtesies, religious rituals
Communicating without receiving a response
Fitting none of existing categories

Examples of Dementia Care Mapping from:
Brooker, DJ & Surr, C 2006, Dementia Care Mapping initial validation of DCM 8 in UK field trials", *Int J Geriatr Psychiatry*, Vol. 21, pp. 1018–1025.
Mansah, M, Coulon, L & Brown, P 2008, "A mapper's reflection on Dementia Care Mapping with older residents living in a nursing home", *International Journal of Older People Nursing,* Vol. 3, pp.113–120.

APPENDIX 10 TABLE OF ANALYSIS FOR EACH CENTRAL PARTICIPANT

Name:

Step 2: 'When', 'Where', 'Who' of Local Communication Context When Where Who- With whom seeking to resonate, and performed to, role of other, stage of relationship, what purpose	Synopses of interactions with person over the period Initial Plot Possible meanings 'why' of the person's voice at the time Initial subject headings
Step 3 a: **'How'** ***Linguistic Analysis*** (Muller & Schrauf 2014; Schrauf & Iris 2014)	
Details form e.g. greetings, courtesies Describes how co-construction occurs e.g. turn-taking, sequencing over a time period Defines 'the linguistic-cognitive resources of person e.g. capabilities, strategies, devices'	
Step 3 b: **'How' Expressions/ Enactments in Groups** (based on Dementia Care Mapping: Brooker, DJ & Surr, C 2006; Mansah, M, Coulon, L & Brown, P 2008)	
Making verbal comments and/or commentary Making particular sounds Watching and engaged Disengaged, withdrawn Interacting with others in the group non-verbally in e.g. gesture Interacting with others in the group verbally Interacting with others outside the group non-verbally (e.g. residents, staff, family) Interacting with others outside the group verbally (e.g. other residents, staff, family) Expressing silence and ways this is	

expressed Initiating, Asserting Joking, using humor Singing Reminiscing and life storying Expressing ritualized behavior e.g. greeting, courtesies, religious rituals Communicating without receiving response Additional expressions of participating resident fitting none of above	
Step 4: Themes in compiled episodes:	
Step 5: Theological reflection and ethical reflexivity revisited interactive initiative, responses and relationships	Further understanding through applying theory and other perspectives. theology
Step 6: Compilation of Analysis Compiling the data set of central participants with exemplar extracts of episodes under themes	E.g. Social Conventions Identity Agency Storied-life Capability Themes and Meanings

APPENDIX 11 INFORMED CONSENT OF FAMILY MEMBER

INFORMED CONSENT FORM
FOR PARTICIPATION IN RESEARCH
FAMILY MEMBER/FRIEND
(by interview, observation, auditory recording and/or discussion group)

The Voice of the Older Person with advanced dementia in residential aged care (RAC): How does an older person express their voice in RAC?

I ……………………………………………………………………………………………………….

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction/Information Brochure for the research project on "The Voice of the Older Person in Residential Aged Care".

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to being observed with …………………… and to the audio recording of this interaction.
4. I agree to being interviewed and to the audio recording of my information and participation.
5. I am aware that I should retain a copy of the Information Brochure and Consent Form for future reference.
6. I understand that:
    - Due to my participation in this research occurring in the [redacted] setting, my anonymity will not be guaranteed.
    - I may not directly benefit from taking part in this research.
    - I am free to decline to answer particular questions.
    - I am free to ask that the recording/observation be stopped at any time.
    - I am free to withdraw at any time from the session or the research project at any time without disadvantage.

- While the information gained in this research study will be published as explained, I will not be identified or identifiable, and individual information will remain confidential.

Participant's Name……………………………………………………………………..

Participant's signature…………………………………….Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name…………………………….…………………….................

Researcher's signature…………………………………..Date…………………….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of following clause, as appropriate.

To be signed below after collection of the data

I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature…………………………………….Date…………………...

Please return to: Julie Simpson

Sealed Box in ……………………………………………….

APPENDIX 12 SEMI-STRUCTURED INTERVIEW QUESTIONS WITH FAMILY MEMBER

Regarding their relative (a central participant)

What do you consider to be the voice of this person? How would you describe it?

What needs,
requests,
concerns does…………………………………express to you?

How does ……………………usually express their needs, requests or concerns to you?

What else does ………………………………..express that you notice?

How does …………………express this?

What is ……………………………………expressing about their individuality in this?

What do you consider it means to ………………………………when they express themselves?

How do you endeavour to understand what ……………………. is communicating?

Do you always understand what ………………………………..is communicating?

What are the benefits to …………………………………of you listening to them?

Why is it important to you that you understand what ……………………………..is communicating?

How do you seek to develop your understanding of what ……………is communicating?

Does what ……………………….expresses now relate to their personality or their history?

Over the years has their voice changed? If so how? Or why not?

What practices help this person to express their voice?

What practices hinder this person from expressing their voice?

APPENDIX 13 STAFF LETTER OF INTRODUCTION

Associate Professor in Nursing Care of
the Older Person **Ann Harrington,**

School of Nursing and Midwifery
Sturt West Wing (W408)

Sturt Buildings

GPO Box 2100
Adelaide SA 5001

Tel: 082013483
Fax: + 61 8 82761602
ann.harrington@flinders.edu.au

http://www.flinders.edu.au
CRICOS Provider No. 00114A

September, 2017

LETTER OF INTRODUCTION
STAFF MEMBERS

Dear Member of [redacted] Staff,

This letter is to introduce Julie Simpson who is a PhD student in the School of Nursing at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

She is undertaking research leading to the production of a thesis or other publications on the subject of

> **The Voice of the Older Person with advanced dementia in residential aged care (RAC): How does an older person express their voice in RAC?**

Julie Simpson's research project will explore:

1) With residents with advanced dementia themselves, how they express their voice verbally and non-verbally, and what this means to them;
2) And with staff members and family members, what are current and any new practices for promoting the voice of older people with advanced dementia in residential aged care.

Julie would like to invite you to assist with this project by agreeing to be involved in any/or all of the following: being interviewed in a private place; agreeing to being observed in your interactions with individual residents and groups, not including their personal care and hygiene.

Since all involvement in this research project will occur in the [redacted] setting the anonymity of participants cannot be guaranteed. However, be assured that any information provided will be treated in the strictest confidence. The specific content of the interviews will remain confidential. None of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Since she hopes, with the permission of the participants, to make a tape recording of the interviews Julie will seek your consent, on the attached form, to record these situations. She plans to use the recording or a transcription in preparing the thesis, report or other publications, on condition that your name or identity is not revealed. It may be necessary to make the recording available to secretarial assistants (or a transcription service) for transcription, in which case you may be assured that such persons will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8 8201 3483, fax 8 8276 1602 or e-mail ann.harrington@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

Associate Professor in Nursing Care of the Older Person Ann Harrington RN PhD FACN
School of Nursing & Midwifery
Flinders University,
GPO Box 2100
ADELAIDE SA 5001 AUSTRALIA

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 7552). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

APPENDIX 14 STAFF INFORMATION BROCHURE AND REPLY PAGE

What are the ethical guidelines for the research project?

As a PhD student Julie has had to submit to a rigorous ethics process to gain permission to undertake the research project. An ethic of care approach will be the underlying principle for undertaking this research. This approach calls for an ongoing commitment "to act out of care and compassion in ways that benefit the residents, care staff, and the organization that are part of my research". An ethic of care is principled on the researcher's prioritizing of person and relational-centred care.

How will I receive feedback?

Outcomes from the project will be summarised and written up and presented as a final report to [redacted] by the researcher.

How do I agree to participate?

Participation is voluntary, and your work at [redacted] will not be affected in any way if you choose not to participate. You may answer 'no comment' or refuse to answer any questions in the interviews. You are free to withdraw from the research project at any time without effect or consequences.

If you wish to participate please fill in the Reply Page, and return to the Sealed Box in Reception or Staff Dining Room marked "Research" as soon as possible.

STAFF INFORMATION BROCHURE

[redacted]

DATE

INTRODUCTION OF RESEARCH PROJECT

To be undertaken by Julie Simpson,
PhD Student, Flinders University

August - November 2017
January – April 2018

Flinders UNIVERSITY

Thank you for taking time to read this information brochure, and responding if you wish to participate

Introduction

Julie Simpson is a 2nd year PhD Student in the College of Nursing and Health Sciences at Flinders University.

Permission has been granted by [redacted] for Julie to undertake her PhD research project at two of its sites. The title of her research is:

The Voice of the Older Person with Advanced Dementia in Residential Aged Care: How does a resident express their voice in RAC? How is their voice supported by the care team?

Research Supervisors

Julie is supported by a number of supervisors in three ways:

1.Flinders University: Principal supervisor Associate Professor Ann Harrington, College of Nursing & Health Sciences, Ph 8201 3483 if you have any queries or concerns regarding the research project; 2. [redacted]

What is the purpose of the project?

This research project aims to engage older people with advanced dementia, who reside in the dementia houses, and those people who care for them as staff and family/friends. Only those who have given their appropriate consent will be involved.

The objectives of the project are to explore in residential aged care:

- How older people with various types of advanced dementia, enact and express their voice in residential aged care;
- What are the meanings older people, with advanced dementia, give to having voice in residential aged care;
- Current practices and how the culture in residential aged care affects an older person's voice;
- Exemplars of multi-disciplinary practices promoting the voices of older people with various types of advanced dementia.

How will the research project be undertaken?

The research project will be done in 2 interconnecting parts:

Part 1: "Shadowing" /spending time alongside a number of residents (up to 15)

- Auditory recording of a participating resident in conversation with myself; - Observation and notes by myself of residents in individual and group settings with other residents, staff and family;
- Auditory recording of interviews (with consent) of staff members;
- Auditory recording of interviews (with consent) with their family member/friend;
- Reading the progress notes of participating residents.

Part 2: Reflection on data collected from residents as we go along

- By myself
- With staff or family/friend in interviews (5-20 minutes), up to 3 times

What will I be asked to do?

Julie invites you to assist with this project by agreeing to be involved in any/or all of the following:

- consenting to being observed in your interactions (not including personal hygiene care) with individual residents and in groups;
- being interviewed about how residents express their voices for no more than 5-20 minutes, up to 3 times;

Your involvement will only be voluntary, with your signed consent, and at your convenience. If you choose to participate, this will usually occur during residents' normal daily routines and activities, and not include their personal care and hygiene.

The interviews will occur at your convenience, and you may choose to refuse to answer any questions. The interviews, with your permission, will be recorded using a digital voice recorder to help with looking at the results. Once recorded, the interview will be transcribed (typed-up) and stored as a password protected computer file, and then destroyed once the results have been finalised.

There is no obligation to participate. You are free to withdraw from participating in the research project at any time without disadvantage or penalty.

Will I be identifiable by being involved in this study?

As all involvement in the research project will take place in [redacted] anonymous participation is not guaranteed. However, all information given by participants to the researcher will remain confidential.

You will not be identifiable in the eventual thesis, report or other publications. Any identifying information will be removed and the typed-up file stored on a password protected computer and server that only the researcher will have access to.

Are there any risks or discomforts if I am involved?

The researcher anticipates few risks from your involvement in this study. All participation will be sensitively managed and your confidentiality will be maintained. The researcher is a mandated reporter. The researcher will make situated decisions in response to any issues of concern, threat or misconduct which arise. These issues will be discussed with the researcher's primary supervisor as soon as possible.

Where a resident appears unsettled in an interview Julie will contact a staff member immediately, and personally, or with their assistance, seek to settle the resident. She will also courteously terminate the session with them. Their responses will be considered regarding future encounters.

What benefit will I gain being involved in this study?

This research seeks to identify the voices of older people with advanced dementia. How their voices occur, including through the relationships with, and the practices of, staff members and family members/close friends, will be explored. Therefore, this research has implications for assisting in the planning and delivery of services to individual older people, praxis in aged care homes, and the residential aged care sector.

REPLY PAGE (Separate A5 Insert)

Staff Member

How do I agree to participate?

Participation is at all times voluntary, at your convenience, and with your consent. As all involvement in the research project will take place in the [redacted] setting anonymous participation is not guaranteed. However, all information will be confidential. You are free to withdraw from participating in the research project at any time. No participant in the research will receive any payment or inducement to be involved.

If you would like to participate please fill in this page with Your contact details

Name ……………………………………………………………

Contact details (Phone number)…………………………

Please return to the Sealed Box in Reception or the Staff Dining Room, marked “Research”. Julie Simpson will contact you as soon as possible.

REPLY PAGE (Separate A5 Insert)

Staff Member

How do I agree to participate?

Participation is at all times voluntary, at your convenience, and with your consent. As all involvement in the research project will take place in the [redacted] setting anonymous participation is not guaranteed. However, all information will be confidential. You are free to withdraw from participating in the research project at any time. No participant in the research will receive any payment or inducement to be involved.

If you would like to participate please fill in this page with Your contact details

Name ……………………………………………………………

Contact details (Phone number)…………………………

Please return to the Sealed Box in Reception or the Staff Dining Room, marked “Research”. Julie Simpson will contact you as soon as possible.

APPENDIX 15 STAFF INFORMED CONSENT FORM

INFORMED CONSENT FORM
FOR PARTICIPATION IN RESEARCH
STAFF MEMBER
(by interview, observation, auditory recording and/or discussion group)

The Voice of the Older Person with advanced dementia in residential aged care (RAC): How does an older person express their voice in RAC?

I ……………………………………………………………………………………………………

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction/Information Brochure for the research project on "The Voice of the Older Person in Residential Aged Care".

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I agree to my work activities with a resident or group of residents being noted or recorded.
5. I am aware that I should retain a copy of the Information Brochure and Consent Form for future reference.
6. I understand that:

    - I may not directly benefit from taking part in this research.
    - I am free to not answer particular questions, or to ask for my work activity not to be observed or noted.
    - I am free to withdraw from the project at any time.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my role as an employee of [redacted].

- I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

7. I have had the opportunity to discuss taking part in this research with another staff member.

Participant's Name…………………………………………………………………..

Participant's signature…………………………………Date…………………...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name…………………………………………………….................

Researcher's signature………………………………..Date…………………….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of the following clause, as appropriate.

I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature…………………………………Date…………………...

APPENDIX 16 SEMI-STRUCTURED INTERVIEW QUESTIONS WITH STAFF MEMBER

Regarding a specific resident/ or residents with advanced dementia generally

What do you consider to be the voice of the person? How would you describe it?

What needs,
requests,
concerns does…………………………………express to you?

How does ……………………usually express their needs, requests or concerns to you?

What else does ………………………………..express that you notice?

How does …………………express this?

What is ……………………………………expressing about their individuality in this?

What do you consider it means to ………………………………when they express themselves?

How do you endeavour to understand what ……………………. is communicating?

Do you always understand what ………………………………..is communicating?

What are the benefits to …………………………………of you listening to them?

Why is it important to you that you understand what …………………………….is communicating?

How do you seek to develop your understanding of what ……………is communicating?

Does what ……………………expresses now relate to their personality or their history?

Over the years has their voice changed? If so how? Or why not?

What practices help this person to express their voice?

What practices hinder this person from expressing their voice?

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