I Know I Should, but I Haven't

South Australian Baby Boomers
Forever Contemplating Advance Care Directives

Sandra L Bradley

RN, BSc, BArts, BN, Grad Cert (Ed), FRCNA

Submitted for award of Master of Science, Research
(36.0 Units)

Flinders University
Faculty of Health Sciences
School of Nursing and Midwifery

February 2012

Table of Contents

Chapter 1 – Introduction

Chapter 2 – Relationship and Context of ACDs to Boomers

Chapter 3 – Methodological Approach for Identifying Factors Influencing SA Boomer ACD Decision-making

Chapter 4 – Identification of the Factors influencing ACD Decision-making by SA Boomers – Part A

Chapter 5 – Identification of the Factors Influencing ACD Decision-making by SA Boomers – Part B

Chapter 6 – Identification of the Factors Influencing ACD Decision- making by SA Boomers – Part C

Chapter 7 – The Basic Social Psychological Process (BSPP) of Contemplation for ACD Decision-making by SA Boomers

Appendices

Preface

This research was undertaken after conversations I had with Boomers, like myself, about the decisions we would have to make in the future about our healthcare and welfare based on our own experiences of the healthcare system. These conversations led to a desire to pursue in an academic and scholarly fashion the usefulness of advance care directives (ACDs) in protecting autonomy in future decision-making and their utility for Boomers. Advance care directives were rarely seen during the course of my employment as a registered nurse in an acute care environment. Advance care planning (ACP), on the other hand, was being promoted through programs like Respecting Patient Choices (2008) as a means of preserving personal autonomy whilst reducing unwanted and costly medical treatments. I often saw these treatments being applied to the oldest of the old at the expense of their quality of life, as expressed by these patients, yet it seemed that they continued to receive these treatments. I wanted to know why and I also wondered if Boomers would be so willing and acquiescent to do the same. To answer that question, I chose to research this demographic group to see if they were creating ACDs in a manner indicative of their intent to protect their future autonomy in healthcare and welfare decision-making.

The title of this thesis "I know I should, but I haven't" was expressed by all participants in this study in relation to various elements of ACD decision-making for themselves. The relevancy of this statement to other SA Boomers has since been substantiated through discussions with colleagues, friends and acquaintances in conferences and corridors over the five years of this research. If you chuckled when reading this title because it was familiar and relevant to you, welcome to the club.

Abstract

As we grow older, many of us will be asked to assist in making decisions about healthcare and welfare management for those we love and support. This will be especially true for the generation born between 1945 and 1965 known as the Baby Boomers. Involvement in such decision-making may lead Boomers to consider their own future healthcare and welfare management. It remains unclear however whether or to what extent Boomers have considered such decision-making for themselves. Knowing in advance the healthcare and welfare decisions Boomers might make is important for healthcare policy planning, especially in states such as South Australia with high populations of people aged 65 and older. It will be a challenge for the Government of South Australia to preserve personal autonomy in decision-making in an environment of dwindling healthcare resources as the first of whole generations (i.e. the Boomers) retire and enter older age at the same time, something not previously envisioned in earlier generations.

The literature speculates about the types of healthcare Boomers themselves will require in the future but there is little evidence to guide policy makers, academics and others to the extent and type of healthcare this generation will actually demand. One way to provide evidence of this future demand is to study the use of instruments called advance directives (ADs), or in the proposed future vernacular, advance care directives (ACDs), by Boomers for recording their decisions on healthcare and welfare decision-making.

Advance care directives are instruments that define aspects of healthcare and welfare through guardianship and substitute decision-making instructions. These instruments inform others of the individual’s values, including what constitutes a quality of life for them. These instruments are particularly relevant to the Boomer generation as they were the generation that politicised the need for them as part of the consumer choice movement informing the early years of their maturation.

To evaluate Boomer ACD decision-making, this research used a qualitative methodological approach that enabled subjective understanding of the experience of ACD decision-making for a sample of this generation in South Australia. The qualitative methodological approach of classical grounded theory (CGT) was chosen for its ability to explain from the ‘ground up’ basic social and psychological processes influencing human behaviour and practice. Ethical approval was then gained for interviewing a purposive sampling of South Australian Boomer participants on their experience of ACD use. To elicit factors influencing ACD decision-making, semi-structured interviews using audio-tape recording were transcribed verbatim. Data were then coded and analysed using the constant comparative analysis (CCA) method of CGT to uncover the Basic Social Psychological Process (BSPP) underpinning the ACD decision-making of the participants.

Results of this research identified a core category of contemplation to describe the BSPP. Three levels of non-linear contemplating behaviour were found: contemplation of knowledge of ACDs; contemplation of relationships with others for substitute decision-making; and contemplation of actions/inactions for ACD completion. Participants in this research identified that they often moved between these levels of contemplation depending on the context in which ACDs were considered.

Findings from this study reflect what previous research on the frail elderly, chronically and terminally ill have suggested influenced ACD decision-making, such as age, mortality and choice of SDM. What makes this research significant is that the participants in this research were young, in good health and were not a targeted audience for creation of ACDs by advance care planning programs. Their perceptions of ACD use suggest that other factors may be influential in generating contemplation of ACDs *before* people reached ill health or frail age. These factors include experiential knowledge of the healthcare system, favourable SDMs and professional guidance to complete ACDs. If these and other factors named by participants in this study were made available, then ACDs could be completed in a timely manner. If, however, these factors were not available, then some of the participants in this study chose to continue contemplating ACDs.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

……

Sandra L Bradley **Date**

Acknowledgments

I wish to acknowledge and thank the following people and organisations for their support throughout the tenure of this thesis:

First and foremost, my participants, for without their generosity in sharing their concerns, experiences and contemplations with me, this thesis could not have been written;

My husband, Tom, and my mother, Patricia McGoogan, for their support in all ways including listening *ad nauseum* to my discussions on death and dying and Ms Julie Tranfa for in-depth discussion about the spiritual considerations involved in contemplating our own mortality

The rest of my family and friends for their belief in my ability to see this project through;

My supervisors and mentors Dr Anita De Bellis, Dr Evdokia Kalaitzidis, Dr Steve Parker, Dr Sheryl De Lacey, Ms Jean Murray and Ms Kathy Williams for helping me to understand and navigate the maze of ACD components involved with this research subject;

The Nurses Memorial Foundation, SA, Inc for their financial support to attend the 2009 IIQM Qualitative Research Conference in Vancouver, Canada which provided confidence for and substantiation of the research method chosen for this thesis;

The South Australian chapter of the Australian Association of Gerontology for their financial support to present at the 9th International Asia/Oceania Regional Congress of Gerontology and Geriatrics and finally;

Flinders University School of Nursing and Midwifery for providing me with the employment and wherewithal to conduct this research

Abbreviations

AD – Advance Directive

ACD - Advance Care Directive

ACP – Advance Care Planning

Ant Dir – Anticipatory Direction

CCA – Constant Comparative Analysis

CGT – Classical Grounded Theory

EOL – End of Life

EPA – Enduring Power of Attorney

EPG – Enduring Power of Guardian

HCP – Healthcare Professional

LP – Lay Person

MPA – Medical Power of Attorney

QOD – Quality of Death

QOL – Quality of Life

SDM – Substitute Decision-maker

Chapter 1 - Introduction

This research examines the use of advance care directives (ACDs) by a representative sample of South Australian Baby Boomers. The reason for investigating this issue is described in this chapter through identification of the aim, purpose, significance, background, timeliness and context of this research in relation to future healthcare policy planning for this generation in South Australia (SA).

The term ‘advance directive’ was first coined by Kutner (1967, cited in Hong and Lee, 1996) to provide a mechanism for future decision-making for a person at a time when the person may not be capable of voicing these directions for themselves. Advance directives (ADs) come in many forms and in areas where they are legislated and applied may incorporate formal instruments which have been witnessed or verbal instructions to indicate the direction that a substitute decision-maker (SDM) should take (The Clinical, Technical and Ethical Principal Committee (TCTEPC), 2010; Wilkinson et al., 2007). The contemporary forms of various advance directives were developed in the early 1990s in the United States of America (USA) to preserve autonomy in healthcare and welfare decision-making (The SUPPORT Investigators, 1995). In South Australia and nationally, there is currently an attempt being made to create a separate terminology for the advance directives that specifically relate to care arrangements as opposed to financial planning instruments (TCTEPC, 2010) The South Australian Office of the Public Advocate (2003) defined this alternative terminology to mean any one of several instruments used to detail the wishes a person might make about healthcare or guardianship in future care scenarios when they are unable, through lack of competence or capacity, to participate in decision-making about their care. The more recent adoption of the term advance *care* directive (ACD) has indicated a shift in emphasis of the primary function of these instruments to provide care decisions rather than financial decisions. In consideration of the proposed changes in terminology to be used in future South Australia legislative processes in this area, this research has used the terminology of advance care directive (ACD) throughout except when directly referring to the Power or Enduring Power of Attorney (EPA) or other states/territories or countries instruments which differ in structure to Australia's. On these occasions, the terminology of advance directive (AD) has been used. The application of these terms in this manner is consistent with the recommendations of the *National Framework for Advance Care Directives* (TCTEPC, 2010).

The change in terminology has been suggested in response to an increasing awareness that people in some states complete financial advance directives thinking they are instruments of care decision-making with attendant rights and responsibilities (TCTEPC, 2010). Research has found that completion and presentation of financial instruments for care decision-making generates confusion for healthcare professionals (HCPs) administering treatment if they are presented with a financial instrument instead of a care directive during crisis care management (TCTEPC, 2011; Brown and Jarrad, 2005b).

This need to clarify the terminology as used in this research has arisen as a result of advance directives in Australia having been constructed in different ways and legislated under a variety of laws and Acts. A listing of the instruments identified as ADs or ACDs and the powers conveyed as represented in South Australia and are in Appendix 1 – Glossary of Terms.

Kerridge, et al. (2009b) describe that some form of AD has been available in many countries throughout the world for several centuries to protect financial assets. The advent of ACDs however emerged during the 1990s at the same time that a particular generation, called the Baby Boomer generation, was maturing (Kaplan, 2009; Rubin, 2007; Gillick, 2006). Their importance to ACD decision-making will be established in both this chapter and the next, Chapter Two – A Contextual Literature Review.

The Australian Bureau of Statistics (ABS) (2003) defined the Boomer generation in Australia as those born between the years 1945 to 1964. These years vary slightly in the literature depending on the country being researched. Nevertheless, this generation came of age during a time when societal norms were being challenged on many fronts and produced the feminist, civil rights and consumer choice movements to name just a few. These movements directly challenged the authoritarian and paternalistic traditions of the past and in many cases conquered them in favour of individual choice (Kaplan, 2009; Higgs, et al. 2003; Center for Aging Research and Educational Services (CARES), 1997). This freedom to think and live without constraint led to technological advancements catering for new ways of thinking about people and their place in society. Examples of these advancements included computerised technology; advances in air and space travel; and the concerted ability to provide higher education to greater numbers of people in society (Kaplan, 2009).

Of most importance to this research was the influence that advancements in medical technology had on individual choice in healthcare and welfare management. From the 1970s onwards, the Boomer generation became concerned about the impact on quality of life (QOL) of medical advancements that prolonged life and arrested the dying process (Rubin, 2007; Gillick, 2006; Brown & Jarrad, 2005b; Lynn, 2005). Their concern reflected the consequences to others with responsibility for managing the care of people who were no longer able to care for themselves and eventuated in the creation of ACDs to protect individual choice in healthcare and welfare decision-making.

The resultant effects of medical advancements prolonging life has contributed to a doubling of the world’s population from 3 billion to 7 billion people in less than 50 years (ABS, 2010b; 2009). Those aged 65 and over now account for 8% (506 million) of the world’s population in 2009 (ABS, 2010b; 2009). These numbers are expected to double or triple in many countries around the world over the next thirty years (ABS,2010b; 2009; 2006c). For some parts of the world, the expansion in the number of people aged 65 and older has happened at the same time that the number of younger people entering the workforce has declined due to lower fertility rates brought about by the invention of the birth control pill during the social revolutions of the 1960s (ABS, 2010b; 2009; 2006c; 1997; Kaplan, 2009). Australia has not been immune from these kinds of demographic shifts in the population. Australian states such as South Australia are expected to have more people over the age of 65 than under the age of 15 by 2030 without immigration of younger people to the state (ABS, 2010b). This demographic shift is significant when considering QOL in future healthcare and welfare decision-making as people continue to age with chronic illness and healthcare resources become stretched (ABS, 2010b; Hugo et al. 2009).

Evidence from the ABS indicated that more people are living longer with multiple states of chronic illness that impact not only on their QOL but also their ability to participate in paid employment (ABS, 2006a; 2006b; 2005). In South Australia, this trend has equated to approximately 400,000 Boomers becoming part of the growing network of ageing workers living and working with chronic health conditions such as diabetes (ABS 2006a; 2003). Based on current statistical evidence of the health condition of members of this generation, there are preliminary indications about the types of care they may require in future but their expectations regarding this care are less discernible (ABS, 2006b; 2003).

One way to investigate these expectations is by researching how and if the first of the Boomers, those reaching the traditional retirement age of 65, have been using ACDs to indicate their future healthcare and welfare preferences. Available data thus far indicates that overall less than 15% of eligible South Australians (those 18 and older) have created formal ACDs to protect their personal autonomy in healthcare decision-making (TCTEPC, 2010; Brown & Jarrad, 2005b; Harrison Health Research (HHR), 2004). Should ACDs not be discussed or substitute decision-makers (SDMs) not chosen, then decision-making for Boomers in crisis situations could be left to others who may not know the values of the person they are representing. A possible consequence of such a scenario is that Boomers stand lose control over the last remaining years, days and even moments of their lives. This would be an anathema for the generation that fought hard to enshrine personal autonomy in future healthcare and welfare decision-making through ACDs.

Aim and Purpose of Research

The aim of this research was to explain the factors that influenced ACD decision-making in a sample of Boomers in South Australia. The purpose of doing this research was to contribute original knowledge to the current understanding of ACD decision-making by members of this demographic group within the context of the SA healthcare system. Guiding research on the main question was a sub-set of questions which enabled a more focused approach to exploring the contextual underpinnings of this decision-making.

Research Questions

The primary research question underpinning this research was “What factors influence ACD decision-making by Boomers in South Australia?” This question comprised the following elements:

- What has been the context of historical, ethical, legal, psychological and sociological development of ACDs in relation to Boomers and how has this differed from other demographic groups in the literature?
- Which historical, ethical, legal, psychological and social factors have specifically influenced and acted as enablers or barriers to a sample of South Australian Boomers in their ACD decision-making?
- Based on the findings from this research: what is the overall core category describing the Basic Social Psychological Process (BSPP) involved in ACD decision-making for the Boomer participants of this research and how can knowledge of this process inform future policy planning on ACD use?

To answer these questions, this research has used a qualitative methodology to investigate the subjective experience of ACD decision-making in a sample of SA Boomers. The qualitative methodology chosen was classical grounded theory (CGT) described in greater detail in Chapter Three. Classical grounded theory is a method that generates theory about behaviour and practice from the ‘ground up’ through identification of a basic social psychological process influencing people situated within a particular context. The behaviour investigated in this research was the use of ACDs by this sample of SA Boomers. The practice investigated was the use of ACDs by this demographic group to protect their autonomy in future healthcare and welfare decision-making. Findings from this research will contribute original knowledge of the factors influencing this sample of SA Boomers on ACD decision-making within the context of the SA healthcare system.

Significance and Background of Research

The significance of this research lies in its ability to define the actions of a group of people not previously studied with regard to ACD use, being SA Boomers. Boomers, in general, are still at a stage of life where the majority are relatively healthy and for whom many are not yet afflicted with terminal illness or disability requiring residential aged care accommodation (ABS, 2003). This means they are at a prime time of life to complete advance directives as these instruments should ideally be completed by people over the age of 18 when they are in good health and have the capacity to understand the consequences of their decision-making (Office of the Public Advocate South Australia (OPASA), 2004). However, the literature on AD or ACD use revealed that previous research conducted on this issue has focused largely on the frail elderly, those in residential aged care and the terminally ill (Lopez, et al. 2010; Bravo, et al. 2008; Pautex, et al. 2008; Brown, 2006; Fried, et al. 2006; Nolan, et al. 2005;The SUPPORT Investigators, 1995). This has limited the evidence on the effect and application of these instruments by those who are younger, healthier or who may have lost capacity to engage with ACDs through illnesses such as dementia. The frail aged and terminally ill have been most often studied because these demographic groups represent a health state when death is imminent and ACDs are required to ensure a ‘good death’ for the person involved. In the last several decades, however ACDs have become increasingly important for protecting the autonomy of younger people with chronic illness where repeat hospitalisations, catastrophic collapse, or care arrangements may be required (Anderson, 2009; Camhi, et al. 2009). Crisis events that may necessitate ACD decision-making for younger and/or the chronically ill include; accidental trauma, surgery, stroke or cognitive impairment from medication, dementia, mental health illness or other situations involving incapacity or incompetence (Camhi, et al. 2009; Epping-Jordan, et al. 2001; Ritchie, et al. 1998; Rood, 1996).

Two recent court cases in Western Australia and South Australia illustrate how ACDs are becoming important to these emerging groups of people. The judgements of Rossitor and HJ vs Anor set precedents supporting the ACD decisions of younger aged, competent nursing home residents with debilitating diseases who refused food, drink and medication (Kourakis, 2010; Martin, 2009). The judgements supporting the personal autonomy of these individuals in both cases were made because the applicants' requests had been previously identified consistently in multiple versions of ACDs over a period of time that recorded their advance decisions of treatments they would accept and not accept at different stages of their disease trajectory. Having these ACDs and a history of unchanged preferences provided evidence of consistency in their designated values of what constituted quality of life for them. These legal precedents are of significance for Boomers and those with chronic illness choosing to specify in advance their end of life care preferences (Productivity Commission(PC), 2011; Australian Government(AG), 2010; Department of Health and Ageing (DHA), 1999).

Legal decisions such as Rossitor and H v Anor demonstrate that when ACD conversations are conducted early and often with SDMs and HCPs, what a person can expect for healthcare or welfare treatment in the future will be supported. Yet, promotion of ACD discussions to younger and healthier age groups in a timely fashion has not been emphasised in countries where ACDs exist because their more immediate application to the frail aged and terminally ill has taken precedence (Bravo, et al. 2008; Wilkinson, et al. 2007). Not having ACDs at younger ages where chronic illness may require multiple engagements with the healthcare sector over a long period of time risks the possibility of compromised decision-making for such individuals (Hancock, et al. 2007).

Since early 2000, researchers have become more attentive to ACDs for the chronically ill and speculation has increased on the kind of decisions that will be made by groups like the Boomers as they are engaged more often in substitute decision-making for ageing friends and relatives (Humpel & O'Loughlin, 2010;

Robinson et al. 2010; Lynn, 2005; Reisfield & Wilson, 2004; Sampson, et al. 2004; Biegler, et al. 2000). Current evidence is minimal as to whether the experience of substitute decision-making will enhance uptake of ACDs in Boomers, however if Boomers are experiencing ACDs through acting for others as SDMs but hesitate completing these instruments for themselves, then current government initiatives to construct policies promoting ACD use, (e.g. the National Framework for Advance Care Directives) may be ineffective and misconstrued (Australian Broadcasting Corporation (ABC), 2010; AG, 2010b; TCTEPC, 2010; World Health Organisation (WHO), 2009; Australian Government 2020 Summit (AG2020), 2008; Bernstein and Edwards, 2008).Therefore, the significance of this research resides in exploring this issue at a time when Boomers, through living longer, are becoming increasingly exposed to chronic illness in themselves and others and the care decisions that need to be made under these circumstances. The significance of the timeliness and context of this research is described in the following section.

Timeliness and Context of Research

Timeliness of this research correlates with the expected retirement of the first members of the Boomer generation beginning in 2011 in Australia as these Boomers reach the age of 65 (ABS, 2009). The age of 65 is a prime time of life for ACD decision-making as pending retirement and chronic illness force this demographic group to define the quality of life (QOL) they want in their final years as they are confronted with the mortality of those they care for (ABS, 2006a; Humpel, et al. 2009; Matwijiw, 2009a). The timeliness of investigating Boomer decision-making during this life course event is in parallel with South Australian government policy direction for future healthcare resource provision (South Australian Department of Health (SAG), 2007a, 2007b). The South Australian government began investigating advance directive use in South Australia through conducting a review in 2007 and presented the findings of their review in 2008 (SAG, 2008). Based on the recommendations of this review as well as reviews conducted on ACDs in other states, (e.g. New South Wales) a *National*

Framework on Advance Care Directive Use working party was established to bring continuity and consistency in the application and legality of ACDs throughout Australia (TCTEPC, 2010). This working party recently released their report advocating for a national approach to ACD forms, implementation and legislation. Therefore, the context and timeliness of this research resides in the impetus for capturing Boomer retirement planning decision-making in the context of Australian and South Australian government initiatives on ACD promotion and implementation.

These same contextual and time issues have been felt elsewhere around the world as evidenced by the increasing number of published studies on ACD use. This increased research effort on ACD use represents the evolution of philosophical, ethical, religious, medical and legal perspectives on ACDs and advance care planning (ACP) (Chan & Webster, 2010; Kaldjian, et al. 2009; Bravo, et al. 2008; Altmore & Naksook, 2007; Hancock, et al. 2007; Parker, et al. 2007). In addition to research emphasis on this topic, another indicator of the timeliness of this particular research study has been the number of online chat forums, news media presentations and documentaries on end of life (EOL) issues. Social media commentary on EOL care has included the use of the intensive care unit for EOL as well as arguments for and against the legalisation of voluntary euthanasia (VE) (Martin, 2011; Butler, 2010; Hillman, 2010; Wilson, et al. 2010; Dore, 2009). The increase in media coverage of EOL care was largely driven by the increasing number of people, including Boomers, who have experienced the difficulties and intricacies of acting as an SDM for those subject to a delayed death.

Research on the consequences of decisions made by SDMs was explored in studies by Hughes and Baldwin (2006) and Fins, et al. (2005). Their research as well as similar findings by Wendler and Rid (2011) and Salmond (2011) identified that the burden of acting as an SDM for others, especially when conducted over a long period of time for the chronically ill, can create moral and psychological distress for SDMs.

This distress was exacerbated for Boomers acting as SDMs whilst continuing to care for their own young adult or minor children and still being in paid employment. Boomer care duties for two generations at the same time means that they have become the *sandwich generation* (ABS, 2003; CARES, 1997). Governments dependent on Boomers to continue managing both care duties and paid employment are concerned that if Boomers need to leave the workforce to care for others, they will no longer contribute to the tax base but instead claim from it through carer pensions and government financed healthcare (AG, 2010b; Cooper & Hagan, 1999). The diminished tax income base that results will be unable to provide healthcare resources for those receiving care from the Boomers as well as for Boomers themselves (Cooper & Hagan, 1999). Research evidence has also indicated that the care responsibilities of this sandwich generation could create or exacerbate physical and psychological stress in these carers, which is already becoming an issue of concern (Anderson, 2009; AG, 2007; Hughes & Baldwin, 2006).

The matter of the responsibility for provision of complex care for people with chronic illness is particularly critical for South Australia as the literature indicated that this state had the nation’s oldest workforce in the country, with many of those workers employed in healthcare, in particular the residential aged care industry (Sargent, et al. 2009). The rate of need for RACF care has been increasing in combination with an ageing carer workforce and poses particular challenges for meeting future healthcare and welfare demand in this area (PC, 2011; Australian Institute of Health and Welfare (AIHW), 2010a, b, c; Sargent, et al. 2009; AG, 2007; ABS, 2006a). These challenges are expected to be exacerbated by the increase in the number of people developing highly dependent illnesses, such as dementia (Access Economics, 2009; 2005). Perspectives on how to preserve decision-making capacity and respect of personal autonomy for those with cognitive issues in an ethically sustainable manner has been a particular focus of the most recent research literature and government policy direction (Cartwright, 2011; Access Economics, 2009, 2005; Birch & Draper, 2008 et al. 2008; Brooker, 2007; Australian Health Ministers' Conference (AHMC), 2006). Autonomy or self determination generally refers to an individual's capacity to make decisions based on intentional or rational thoughts and actions (Kerridge, et al. 2009a). Advance care directives take autonomy one step further by enabling self-determined future decision-making of both healthcare and welfare arrangements when a person may not be able to voice the actions they would want taken on their behalf (Kerridge, et al. 2009b).

This type of advance autonomous decision-making is evidenced primarily in medical treatment decision-making but also extends to secondary elements of chronic illness and EOL care, such as where people prefer to live as they age and where they prefer to die (e.g. hospital, home or hospice) (Degenholtz, et al. 2004;Hunt, et al. 2001). In accordance with these secondary extensions of decision-making, governments throughout Australia are evaluating future housing arrangements for Boomers as they age, develop chronic illness and choose to die in their place of residence (Beer et al. 2009; McCallum, et al. 2005; Hunt, et al. 2001). Research into these other areas of potential Boomer ACD decision-making has been driven by the economic rationalism framing Australian government policy direction in this area as evidenced in reviews by the Productivity Commission Review into Aged Care and others conducted by the Australian Government over the last decade (PC, 2011; AG2020, 2008; National Health and Hospital Reform Commission(NHHRC), 2008). These reviews have been a direct acknowledgement of the necessity for change in healthcare provision to future generations such as the Boomers, where the emphasis will shift to care in the home or residential aged care facilities rather than hospitals where care is more expensive and less amenable to autonomous decision-making (PC, 2011; Hunt, et al. 2001; Cooper & Hagan, 1999).

Summary

This introductory chapter described the aim, purpose, research questions, significance, background, timeliness and context of this research. The aim and purpose of this research was identified as exploring the factors influencing some members of the generation known as Baby Boomers to complete South

Australian ACDs. The question guiding this research was “What factors influence advance care directive decision-making by Baby Boomers in South Australia?” The methodological approach used was identified as a qualitative methodology called classical grounded theory (CGT). The context of this research described the interest in exploring ACD use by the Boomer generation at this time because they represent a generation entering retirement and extended ageing in numbers never seen before in human history. Governments around the world have expressed concern that this mass retirement and ageing may weaken personal autonomy in healthcare and welfare decision-making if healthcare resources are subject to resource constraints as a result of Boomers exiting the workforce through retirement and to care for others and themselves.

Therefore, the significance of this research lies in investigating ACD decision-making by a group of Boomers in South Australia who are generally healthy, younger and where the research focus has not traditionally linked them to advance care planning (ACP) or ACDs. Exploring this sample of SA Boomers willingness to engage in healthcare and welfare decision-making will provide evidence of the level and extent of healthcare and welfare autonomy some members of this generation may expect in the future. These findings, in turn, may provide insight and suggestions for future government policy direction and continued research to investigate ACD decision-making in this generation.

The following chapter will review the historical, legal, ethical, psychological and societal factors that have influenced other demographic groups in the literature for ACD decision-making for future comparison of these factors with the Boomer participants in this study.