Client and staff experiences of goal setting and attainment in Transition Care Program

by

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Thesis

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List of abbreviations

ABS	Australian Bureau of Statistics
ACSQHC	Australian Council for Safety and Quality in Health Care
AHA	Allied Health Assistant
AHMAC	Australian Health Ministers Advisory Council
AHSRI	Australian Health Services Research Institute
AIHW	Australian Institute of Health and Welfare
AROC	Australasian Rehabilitation Outcomes Centre
CASP	Critical Appraisal Skills Program
DOH	Department of Health
HCP	Health Care Practitioner
KPI	Key Performance Indicator
LOS	Length of Stay
mBI	modified Barthel Index
MCID	Minimal Clinically Important Difference
PCC	Person Centred Care
SDM	Shared Decision Making
TCP	Transition Care Program

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THESIS SUMMARY

Background: Goals are a fundamental component of health care and promote person centred practice by encouraging collaborative discussions and shared decision making between patient and health care practitioner. Transition Care Program (TCP) is a federally funded, goal-orientated, therapy-focused program that provides additional time after an acute health event for older adults to improve functional ability and decide on final discharge destination. This research investigated the client and staff experiences of goals in TCP.

Research Question: "What are the lived experiences of older adults and staff in goal setting and pursuit at TCP?"

Methods: Perceptions and experiences of goal setting and pursuit in TCP were explored by interviews with clients and focus groups with staff. An interview schedule for clients was utilized at admission, discharge and three months after discharge. The same schedule was used in the focus groups with staff. All discussions were transcribed verbatim. Concepts were discussed between the three researchers and related back to the research question for relevance and true depiction of the phenomenon being studied.

Results: Clients' goals were to go home and return to normal; goals that staff found too broad for the purpose of the program. Going to residential care instead of home was distressing for clients and establishing a 'new normal' required time and support. Clients were hampered by mental and physical fatigue, which affected them throughout their journey with TCP. Support bolstered mood and ability, although it changed at different points in the journey. Staff use a language of recovery rather than goals, and the focus on daily activity and function does not align with client understanding of goals. Process and system barriers were identified.

Discussion: Uncertainty created distress for clients at each time point, which manifested in fatigue and non-engagement. Consistent communication is necessary to avoid ambiguity and enhance shared decision making for goals. Broad client goals can be integrated into the service.

Recommendations: This research provides opportunity to improve person centred care for older adults by integrating consistent language and addressing service barriers in clinical practice. Further research is warranted to investigate goal setting and pursuit for older adults with cognitive or communication deficits and on the psychological and emotional effects of fatigue.

STRUCTURE OF THESIS

This thesis is divided into eight chapters. The first chapter is an introduction to the thesis, providing a rationale for undertaking the research and states the research question.

Chapter two summarises the background literature for the two areas under investigation, namely goal theories and the relevance for older adults. It provides background context for the setting, Transition Care Program (TCP).

Chapter three is a systematic review and meta-synthesis of patient experiences of goals in the health system. This chapter examines the evidence of patient-centeredness in goal identification, pursuit and attainment within health services.

Chapter four explores the methodology for the research. It describes the history and philosophy of hermeneutic phenomenology and the key principles of this methodology in investigating the personal experience of goals in TCP.

Chapter five describes the methods undertaken in this research, and the application of the hermeneutic phenomenological methodology to interviews with clients and focus groups with staff for investigating experiences of goals in TCP.

Chapter six provides the results of interviews with client participants and their experiences of goals in TCP.

Chapter seven presents the results of focus group discussions with staff and their experiences of goals in TCP.

Chapter eight provides an overall discussion of the study for older adults and staff experiences of goals in TCP.

Chapter nine outlines the recommendations for clinical practice, health policy and further research.

DECLARATION

“I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and

2. 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.”

Nicola Ruth Baker
4th March 2019

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This thesis is dedicated to the past, present and future clients in TCP – hoping the additional time in the program provides an improved functional status so you can get home and back to normal!

CHAPTER 1 INTRODUCTION

Ageing population and hospital

The life expectancy of Australians is increasing. In 2016, 3.7 million people, or 15% of the Australian population were aged 65 years or older and this is projected to increase to 8.7 million (22% of the population) by 2056 (AIHW, 2018). Older adults are more likely to have multiple comorbidities placing them at risk of losing function (Buchner & Wagner, 1992). However, the number of years free of disability associated with ageing is also increasing. Therefore, the percentage of severe or profound core activity limitations with ageing, such as reduced mobility, self-care, or communication, is reducing (ABS, 2016).

Despite this reduction in disability 20%, or nearly 2 million, Australian hospital emergency presentations during 2016 were for patients aged 65 years and over (AIHW 2018). Once admitted to hospital, older adults are at risk of losing function (Grill, Ewart, Chatterji, Konstanjsek, & Stucki, 2005). This occurs due to the nature of the hospital environment that promotes bed rest, and reduction in nutritional intake and hydration, which can decrease energy levels and the ability of older people to participate in their treatment and recovery. This further increases the risk of physical or cognitive decline (Iwashyna, Ely, Smith & Langa, 2010).

Furthermore, a reduction in physical function in older people during hospitalization is also associated with increased rates of depression (Street, O'Connor & Robinson, 2007) which exacerbates the risk of functional decline (Covinsky et al., 2003). Functional decline is considered the greatest contributor for lengthened hospital stays in older adults (Baztán, Suárez-García, López-Arrieta, Rodríguez-Mañas, & Rodríguez-Artalejo, 2009) and increased level of care on discharge back to the community (Koenig et al., 1999). Additionally, the combination of reduced function with previous cognitive impairment or the cognitive impacts of illness, such as disorientation, confusion or delirium, make the elderly hospitalized population more vulnerable to falls (Vassallo et al., 1999) and frailty (Covinsky et al., 2003) which further slows recovery from the hospital stay. Complicating social factors such as limited social support or negative family attitudes and the likelihood of living alone also increase with age (ABS, 2017). These social factors, combined with co-morbidities, are all indicators for a less successful transition home from hospital (Jacob & Poletick 2008). The personal cost of a readmission to hospital is, at minimum, emotional and physical instability, with the possibility of a sentinel event or death (Scott, 2010). The health economic cost for readmissions is substantial. Based on 0.2% of patients being readmitted and the annual Australian health cost of $28 billion (AIHW, 2017b), the financial cost of readmission to Australia is estimated to be $56 million annually. Acute hospitals that provide functional maintenance programs, which practice activities of daily living, mobility and self-care activities, have been shown to reduce patients' functional decline at the time of discharge (Flood et al., 2018). In the subacute sector, key purpose of rehabilitation services is to restore functional decline due to a health condition or hospital admission (AIHW, 2018).

Person centred care (PCC) is a term that encompasses patient participation and open communication between the staff and patient (Kitson, Marshall, Bassett, & Zeitz, 2013). Person centred care places patients' needs and wishes at the centre of discussions regarding their health care and ensures that collaborative decisions are made (Epstein & Street, 2011). Shared decision-making (SDM) is defined as a process of presenting choices, explaining possibilities and assisting patients to explore options to make decisions (Elwyn et al., 2012). Shared decision making is an essential component of PCC and considers patients' preferences to develop a shared understanding of treatment and management options (Hoffmann, Jansen, & Glasziou, 2018). Effective SDM has been demonstrated to enhance PCC by improving the patient's mental and physical health status and reducing length of stay in hospital (Barry & Edgman-Levitan, 2012). Patient goals are used by health services to articulate shared decisions (Elwyn et al., 2012).

A goal is defined in the Oxford Dictionary as "*the object of a person's ambition or effort; an aim or desired result*" (Oxford University Press, 2018). Hence, goals provide both the motivation to change the current status and the focus for what is possible in the future. Goal attainment requires motivation (Resnick, 1998) which may be intrinsic or extrinsic to an individual. Intrinsic motivation is described by Ryan and Deci (2000a) as an internal driver for gain, with the motivation being the interest in, or enjoyment of, the activity itself. Thus, in relation to goal attainment, the intrinsic motivation is the satisfaction or feeling of self-worth from pursuing the goals. Extrinsic motivation is as external driver for the attainment of a future goal. In the context of goal attainment, the extrinsic motivation provides a way to identify progress towards the new goal or desired result (Ryan & Deci, 2000a).

For successful goal attainment, people need to be committed to achieving their goal and believe it is within their capability (Locke & Latham, 2006). They also require flexibility and adaptability to manage different opportunities and limitations that occur during the process of goal pursuit (Ebner, Freund & Baltes, 2006). Goal attainment also depends on a degree of self-efficacy, which is the "beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments" (Bandura, 1997, p. 3). In relation to goals, self-efficacy is related to self-reflection and self-regulation. Bandura explained that behaviour would not change without anticipation of consequences, active planning, self-regulation of reactions and modification of thought processes for the planned change. This theory suggests that belief in one's ability to influence the outcome is stronger in people with higher self-efficacy. Further, some self-doubt provides an incentive to acquire knowledge or skills and high self-confidence may provide incentive to focus on activities considered worth pursuing

(Bandura & Locke, 2003).

Goal setting is a conscious intention to regulate or change behaviour by identifying direction and acquiring task-relevant information and approaches (Locke & Latham, 2002). It is facilitated by SDM, where the staff member provides information about different options and the processes available for achieving goals. Goal identification and attainment occur throughout the patient's journey in the health system, from the hyper-acute emergency department, through the hospital, to sub-acute services and into the community. Goal processes in health care differ according to a range of factors including the patient, staff member, service and setting. No single method has been consistently identified (Rosewilliam, Roskell, & Pandyan, 2011; Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013) because a single approach does not accommodate the unique requirements of each individual (Phillips & Gully, 1997).

Goal setting with older people in health settings results in enhanced functional ability such as walking and transfers, self-care and cognitive ability (Kus, Muller, Strobl & Grill, 2011), life satisfaction (Aberg, 2008), self-reported quality of life, emotional status and self-efficacy (Levack et al., 2016), reduced nursing home admissions and reduced mortality (Bachmann et al., 2010). In addition, patient motivation, satisfaction and self- efficacy in health services are facilitated by goal setting (Bodenheimer & Handley, 2009).

The mean age of Australian rehabilitation inpatients in 2017 was 74.2 years (AHSRI, 2017) and there are benefits for older adult patients to participate in goal setting as part of rehabilitation (Levack et al., 2016). Patient motivation and self-efficacy is essential for engagement in rehabilitation services (Jones & Riazi, 2011). Specifically, goal discussions are used to facilitate goal setting between patients and staff for specific conditions such as stroke (Levack, Dean, Siegert & McPherson, 2011; Rosewilliam et al., 2011; Sugavanam et al., 2013); polyarthritis,(Arends, Bode, Taal, & Van de Laar, 2013), acquired brain injury (Plant, Tyson, Kirk, & Parsons, 2016) and cancer (Rose et al., 2004). In addition to physical conditions, the benefits of goal setting and attainment in cognitive rehabilitation are also identified (Clare, Evans, Parkinson, Woods & Linden, 2011). Despite the depth of literature on the importance of goal setting in rehabilitation, and the importance of functional maintenance goals for older adults (Ebner, Freund, & Baltes, 2006), there is limited literature exploring older patients' experiences of goal setting and attainment in health services.

Transition Care Program

Transitions are defined as the transfer between health services, such as from hospital back to the community. Transitions between health services require effective handover communication between the two services and necessarily involve patients in the conversations to ensure that essential information is shared (ACSQHC, 2017). Successful transitions occur when the patient remains living at home after discharge from hospital. Failed transitions can be measured by presentations at emergency department, readmission to hospital or death (Jacob & Poletick, 2008). Failed transitions are more likely in the older population due to increased frailty, multiple co-morbidities effecting longer hospital stays, and the social aspects of living alone (Scott, 2010). In addition, Masters (2008) identified that successful transition from the acute hospital is dependent on effective communication between hospitals, patient case managers and care providers (Masters, Halbert & Crotty, 2008).

In response to the growing need to promote better transition home, a national workgroup was formed to address the care of older Australians (AHMAC, 2005). As part of the national policy "Investing in Australia's Aged Care: More Places, Better Care" (DoHA, 2004), the Transition Care Program (TCP) was created. The TCP was designed as a restorative program for older adults after an acute, inpatient hospital episode, allowing additional time to finalize long-term care arrangements (Gray et al., 2012). TCP is a "time-limited [up to 12 weeks], goal-oriented and therapy-focused" program (TCP guidelines, Australian Government 2015, p. 5). The program aims to improve function through enhancing physical, cognitive and psychosocial capability by means of restorative processes, personal care and case management (Gray, Travers, Bartlett, Crotty, & Cameron, 2008). The program's objectives are to avoid recurrent readmissions to hospital, support eventual discharge home, and avoid residential care placement (Gray et al., 2012).

Federal funding for TCP is provided to each state or territory in Australia, with each program coordinated and delivered independently. The program is provided either in a residential care facility or at home. An Aged Care Assessment Team (ACAT) approval for acceptance into TCP is required and this is performed whilst the patient is in the acute hospital. The approval recommends the most appropriate level of support and discharge venue most appropriate to receive this support. The ACAT decision regarding the patient's ability to improve function must be made in conjunction with the patient, their family, and the referring hospital multidisciplinary team. The team assesses physical and cognitive status, as well as psychosocial needs. The ACAT assessment becomes the care plan that identifies goals to improve function. Once the ACAT assessment is complete, the TCP liaison staff member meets the patient and their family in the acute hospital to develop a goal-oriented therapy program. Communication incorporating the patient's goals forms part of the handover between the acute hospital and TCP. Admission to TCP occurs directly from hospital. The patient's functional ability is measured via the modified Barthel Index (mBI), on both entry to and exit from TCP. The mBI assesses the ability of an individual with a neuromuscular or musculoskeletal disorder to care for themselves by scoring help required for toilet use including bladder and bowel control, grooming, dressing, bathing, feeding, transfers, mobility and stairs (Mahoney, 1965). Scores range from zero to 15 per item, with zero being fully dependent and 15, independent. There is no established Minimally Clinically Important Difference (MCID) for the mBI in this population, although the literature has suggested an estimate of 13 points from admission to discharge (de Morton, Brusco, Wood, Lawler, & Taylor, 2011).

Functional improvement in TCP is described in a “goal-oriented care plan for the care recipient” (TCP guidelines, 2015, p. 46). Goals are extrapolated from the care plan and inform the intervention provided in TCP, which includes low level therapy, recreational and diversional activities to assist the client to restore function and become more independent. Once admitted to TCP, the comprehensive care plan involves family, where available, to inform discharge planning from TCP (Masters et al., 2008).

As part of TCP, case management is offered to the older adult to review their progress in line with their goals and care plan. National expectations of TCP in Australia include functional restoration, return home, and the avoidance of readmission to hospital or admission to residential care. These expectations are measured by the Key Performance Indicators (KPIs) of bed occupancy, length of stay (LOS), hospital readmission rates, discharge destination and change in modified Barthel Index (mBI). Goals are a fundamental component of TCP but do not currently relate to the KPIs. To date the effectiveness of goal setting and attainment and the patient and staff perspectives of goal setting and attainment in TCP have not been evaluated.

The person at the core of this research is referred to as a ‘patient’ in the hospital setting, due to their situation in the acute sector, being the recipient of care. With reference to the literature, there are ‘*differing relationships and differing power dynamics’* in different health settings (McLaughlin, 2009 p.2). In this thesis, the terminology is consciously changed to ‘client’ when referencing transition from hospital and back into the community, which includes TCP. The TCP is restorative care and neither acute nor sub-acute hospital. Whilst the person at the core of the research is still a recipient of ‘care’, TCP is a non-medicalised program offering personal support and low intensity therapy.

Research question

This research is designed to investigate the client and staff experiences of goal setting, pursuit and attainment. It answers the research question ‘“What are the lived experiences of older adults and staff in goal setting and pursuit at TCP?”

CHAPTER 2 BACKGROUND LITERATURE

This chapter provides the outcome of literature review to support this research. It includes information about goal setting theories as a means of behaviour change, the barriers and facilitators to goal setting in health, and the implications of goals for older adults and staff in TCP.

Goal setting theories

In the context of health and wellbeing, goals are used as a tool to discuss and negotiate key priorities for patient treatment, therapy or self-management over a specified period (Gollwitzer & Oettingen, 1998). Goals provide the focus for conversations and SDM between patient and staff member. Shared decision making is essential whenever a decision point is reached (Coulter & Collins 2011) and is central to effective person centred care (Holliday, Cano, Freeman & Playford, 2007).

Goals provide the opportunity for people to identify and pursue a healthier or improved future state that encompasses physical, psychological, social or mental aspects of a person's health and wellbeing (DOH, 2016). Goal setting and pursuit are applicable across all health systems, including acute (Muller, Strobel & Grill, 2011), sub-acute (Leach, Cornwell, Fleming & Haines, 2010) and rehabilitation (Levack, Taylor et al., 2006), community primary care (Bodenheimer & Handley, 2009) and chronic disease self-management (Lawn & Schoo, 2010).

Person centred care focuses on achieving appropriate health decisions when patients and staff make decisions together about the patient's options. Patients' preferences, goals and concerns are considered together with the clinician's knowledge of evidence on relative benefits, risks or uncertainties (Schulman-Green, Naik, Bradley, McCorkle & Bogardus, 2006). Patients are encouraged to consider the benefits or hazards for the various options before communicating their preferences with the clinician (Rise et al., 2013). In the rehabilitation and restorative field of health, the staff member is the facilitator of change; that is, they function as a coach (Jacobs, 2011). However, patient adherence to a rehabilitation intervention is strongly related to their health beliefs and self-efficacy (Ryan, Patrick, Deci, & Williams, 2008). Hence, uncertainty regarding the prognosis of recovery can decrease participation in rehabilitation (Rosewilliam, Sintler, Pandyan, Skelton & Roskell, 2016). Further, patient progression in rehabilitation and restorative care is dependent on ongoing participation in SDM and therapy. As a result, participation is essential for, and one of the benefits of, goal setting.

Several methodologies exist for goal setting and pursuit, and these have been shown to vary according to the context and setting. Similarly, there is no single best approach (Sugavanam, Mead, Bulley, Donaghy, & van Wijck, 2013) or single instrument to measure goal attainment (Stevens, Berurskens, Koke, & van der Weijden 2013). Locke and Latham (2002) found that people perform higher when given a specific, challenging goal and that increased motivation for goal attainment is associated with a higher degree of difficulty, the goal's relative meaning to person and their commitment to pursuing the goal (Locke and Latham, 2002).

Benefits of goals

The process of discussion and negotiation to develop goals is beneficial to both patients and staff. Goals have been identified as a means to motivate and engage clients (Levack, Dean, McPherson & Siegert, 2006) and promote client participation (Wressle, Eeg-Olofsson, Marcusson & Hendriksson, 2002). Goal setting also enhances the therapeutic relationship (Holliday, Antoun & Playford, 2005; McClain, 2004) which is necessary for PCC. Adherence to long-term therapies is essential for successful outcomes, for example with self-management of chronic diseases (WHO, 2003). Goals have been show to provide a means to engage the client, create a therapeutic relationship, increase client adherence to therapy interventions (Hall, Ferreira, Maher, Latimer & Ferreira, 2010) and improve patient outcomes (Bearon, Crowley, Chandler, Robbins & Studenski, 2000).

Goals can vary in their focus. For example, in healthcare services goals can be set with patients regarding symptom management, therapy intervention, functional status or return to social activities. Flexibility in the goal approach is essential due to the different patient populations and rationale for goals, including the time-frame set for goal attainment, characteristics of the goal set, and degree of difficulty or detail within the goal (Locke & Latham, 2002). Goals provide a cohesive direction for staff (Black, Brock, Kennedy & McKenzie, 2010) and can be used to measure progress for clinical outcomes and discharge plans (Sugavanam et al., 2013).

Terminology regarding goals changes according to the service setting and context (Playford, Siegert, Levack & Freeman, 2009). For the purpose of this research, goal setting or planning describes the method for identifying and negotiating goals, goal pursuit is the activity, task or treatment that works towards goal attainment, and goal attainment is the achievement of the identified goals (Siegert & Levack, 2015).

Facilitators for goal setting

Some of the facilitators of goal identification and pursuit include tools to measure progress and the use of consistent, explicit language. Structured tools can enhance the process of goal setting and these tools vary according to the service in which the patient is admitted. Some regularly used tools that are discussed in the literature are motivational interviewing (Miller & Rollnick, 2012), Goal Assessment Scale (Turner-Stokes, 2009), Canadian Occupational Performance Measure (COPM) (Colquhoun, Letts, Law, MacDermid & Edwards, 2010), and patient decision aids (Coulter et al., 2013).

Explicit communication assists with SDM and goal setting. This includes consistent language used by the staff and team (Sugavanam et al., 2013) so that goals are clearly understood by both patient and staff member. Making goals explicit to the entire team provides a shared vision so that goal pursuit is consistent. When the goal setting is individualized, there is the opportunity for SDM and the ability to identify, discuss and avoid unrealistic goals (Plant et al., 2016). This is particularly important for older adults who have more co-morbidities than their younger counterparts.

Barriers to goal setting

For many patients in the health setting, the word ‘goal’ may be unfamiliar, often having not set goals in the past. For those patients who are familiar with goal setting, former experience may have been coercive (for example, at school or work) so the process may be seen negatively by some adults, who may try to avoid goals within health systems as a consequence (Cott, 2004).

Shared decisions are hampered when there is disagreement between patients and staff regarding the expected goals. Differences can occur between patient values and the staff expectations of care interactions (Epstein & Street, 2011). Patients tend to have broad, holistic needs, hopes and expectations and want to be heard and understood (Schellinger, Anderson, Frazer, & Cain, 2018). The implicit expectation of the staff member that the patient can conceptualize a future and identify a different future state to attain may not be realistic. In addition, assumptions exist that patients value self-determination and are willing to discuss their personal goals during the clinical meeting (Schulman-Green et al., 2006). Patients’ interpersonal characteristics may affect their ability to identify and enact goals (Southerland et al., 2016). Patient goals may differ from their carers and staff members (Bradley et al., 2000). There is suggestion that family caregivers choose goals related to symptom or health condition management (Kuluski et al., 2013) and that staff prefer to choose finite, measurable goals that fit with the system or service they are in (Almborg, Ulander, Thulin & Berg, 2009). The terminology for goals may be unfamiliar to patients and the processes involved with goal identification can create confusion, particularly regarding the patient's role (Sugavanam et al., 2013). This may be exacerbated when patients do not see the relevance of goals to their functional status (Taylor et al., 2012), are not ready to consider goals due to their cognition or communication deficit, or there is conflict between patient and staff or family (Laver, Halbert, Stewart & Crotty, 2010).

Conditional goal setting is the inclination to consider high order goals, such as happiness, as conditional upon the attainment of lower order goals such as physical function (Hadley & MacLeod, 2010). Conditional goal setters with poor physical health are more prone to depression. This negatively affects these goal setters' perceived ability to achieve goals (Street et al., 2007). Conversely, there is more anticipation and expectation of the future in day therapy centres where patients identify the positives of social contact, regular exercise and an energizing spark from the social interaction (Tollen, Fredriksson & Kamwendo, 2007). Another challenge is how the person deals with goal non-attainment and difficulties have been identified with self-regulation along the continuum of disengagement, re-engagement and creation of new goals (Wrosch, Rueggeberg & Hoppmann, 2013).

Time is required for the staff member to sit with the patient and assist them to identify goals, which leaves less time available for other activities with the patient such as treatment or therapy. This can increase staff stress to meet external pressures of time or funding to drive treatment (Leach et al., 2010). A balance between patient centred care and the clinical necessity to meet treatment or service requirements within budget and with finite resources is an ethical dilemma that is not easily resolved (Levack, Siegert, & Pickering, 2014). There are further barriers to patient goal setting when the staff member is less experienced or there are inconsistent approaches to goal setting (Scobbie, Dixon & Wyke, 2011). Clinicians' perceived need to control the process regarding their professional responsibilities aligns with their response to contractual, legislative, and professional requirements (Levack, Dean, Siegert & McPherson, 2006). The use of 'SMART' (specific, measurable, achievable, relevant and time-bound) goals help patients identify tangible goals and simultaneously produce a quantifiable outcome measure to match external pressures of discharge planning and length of stay (Levack et al., 2011; Rosewilliam et al., 2011). This requirement for goals to be SMART does not always fit neatly with the patient's goal but with the goal criteria for the work place and service, such as the expectations on discharge planning and length of stay (Bradley et al., 2000).

There is a relationship between patient goals and the psychosocial aspects of coping, isolation and social activities (Glazier, Schuman, Keltz, Vally, & Glazier, 2004). Evidence from chronic disease self-management programs shows, for example, that 30% of goals are psychosocial rather than directly related to a single medical condition or discipline-specific point of contact (Barlow, Bancroft, & Turner, 2005).

Behaviour Change theories

Goals in TCP aim to increase function by facilitating behaviour change in an individual. Many different theories exist for the person's health behaviour change through goal setting, and it is not the intent of this thesis to cover them all. However, a brief examination of the historical perspectives of goal setting through behaviour change theories helps to provide context.

Cognitive Dissonance Theory: In the 1950's Leon Fessinger (1918-1999) identified Cognitive Dissonance Theory. This describes the inconsistency between two thoughts that create conflict. The theory proposes that to reduce the conflict and thereby the dissonance, there are essentially three ways to address the dissonance: the person needs to change their thought; add a new thought that confirms beliefs, for example improved health literacy; or trivialize the inconsistency. By addressing the dissonance, the person may change their behaviour.

The Health Belief Model: Rosenstock (1974) describes internal motivations for changing behaviour. The model requires the person to identify threats to their health and the belief that benefits of changing behaviour outweigh the obstacles. It places importance on the person understanding their condition, the available supports, and how to address the changes required. It is therefore reliant on a degree of health literacy. The emphasis in this model is the person's active engagement in their own health care. The limitation of this theory is that it does not consider the social determinants of health, which may affect health literacy, attitude or engagement.

Theory of Reasoned Action: The broad basis of the health belief model was modified to the Theory of Reasoned Action (Fishbein & Ajzen, 1975) which purports that action relies on a person's perceptions about the consequences of a behaviour before undertaking that behaviour. Attitudes are intrinsically and extrinsically influenced: intrinsically by the person's own positive or negative perceptions of the behaviour; and, extrinsically by society's perception of the behaviour. These influences promote the intention to perform a behaviour and subsequently change a behaviour. The limitations of this theoretical basis are that attitudes and beliefs are willing to change and that the person has full control of the proposed behaviour.

Social Cognitive Theory: Bandura identified Social Cognitive Theory (Bandura, 1986). The cognitive concept of self-efficacy was first described here, and was related to self-reflection and self-regulation. Bandura explained that behaviour would not change without anticipation of consequences, active planning, self-regulation of reactions and modification of thought processes for the planned change. This theory suggests that belief in one's ability to influence the outcome is stronger in people with a higher self-efficacy (Bandura, 1986).

Theory of Planned Behaviour: Ajzen (1991) created a theory that evolved from social cognitive theory. The theory of planned behaviour emphasizes that beliefs about behaviours predict intention, and intentions enable the behaviour. Factors that enable or restrict the new behaviour, and opportunities to engage in the behaviour, become the major considerations for planning a new behaviour.

Self-determination Theory: The concept of motivation for behaviour change was further explored and described by Ryan and Deci (2000b) in Self-determination Theory. This identified that intrinsic motivation, or the internal drive to do something because of the positive emotional or cognitive response, is usually stronger and more sustainable than extrinsic, or external, motivation.

Transtheoretical model (TTM): Stage theories suggest that people move through different stages as they engage in new behaviours. There are three broad stages. The initial stage is before any action occurs and named ‘pre-intention’ or ‘pre-contemplation’. The second stage is the ‘intention stage’, where the person has decided to make a change but has not yet acted. The third stage is where intention turns to action. Prochaska and diClemente (1982) described this as the transtheoretical model as it encompasses all the previously mentioned models and can be applied across populations and settings (Prochaska & diClemente, 1982). This model describes different but consistent stages of change a person experiences as they create intentional new behaviours. The stages of pre-contemplation, contemplation, preparation and action were originally thought to move in a linear manner as the person moved forward to achieving their goal. However further research into addictive behaviours by this team described more of a spiraling pattern, where the movement between the stages potentially continues through multiple phases as relapses occur and the person moves back into pre-contemplation and restarts the cycle (Prochaska, diClemente & Norcross, 1992). Understanding this cyclical pattern of unconscious to conscious thought, preparation and action is the key to understanding goal setting and attainment.

Goals and Older adults

Goals provide an opportunity for shared decision making between older adults and clinical staff (Schulman-Green et al., 2006). Clear communication assists with effective exchange of information between both parties. Additional communication considerations may be required for older adults aged 65 years and older due to age-related hearing or vision changes, or language, speech or cognitive changes due to illness or health events. Tools to measure goal attainment in older adult populations are available, such as self-identified goals assessment (SIGA) (Melville, Baltic, Bettcher & Nelson, 2002), Goal Attainment Scale

(GAS) (Toto, Skidmore, Terhorst, Rosen, & Weiner, 2015) or goal menus (Bradley et al., 2000; Glazier, Schuman, Keltz, Vally, & Glazier, 2004).

A difference in the type, number and adherence to goals has been identified across age groups. ‘Motivational selectivity’ in relation to goals describes reducing the number of goals and increasing the focus on them being associated with increased age (Riediger & Freund, 2006). This is consistent with findings by Penningroth (2012) who found that older adults identify fewer goals than their younger counterparts and also that goal preferences change with increasing age (Penningroth & Scott, 2012). Younger adults’ goals tend to be directed to personal and financial growth including knowledge acquisition and future planning. In middle age, goals change to focus more on wellbeing and behaviours that enhance fitness and cognition. As adults age further, the goals focus on minimizing and preventing losses (Penningroth & Scott, 2012). This aligns with research by Riediger, Freund and Baltes (2005) who investigated goal adherence and intensity of goal pursuit between younger and older adults. Their research revealed that older adults persisted more with goal pursuit and showed greater adherence to their goals than the younger cohort (Riediger et al., 2005).

When older adults set goals with the aim of minimizing and reducing physical, mental and social loss, there is a positive correlation between emotional well-being and physical function (Windsor, Burns and Byles, 2012). In studies assessing the relationship between depression and physical capability, older adults’ depression rates and functional disability increased over time, but so did their capacity to adjust (Dunne, Wrosch & Miller, 2011). According to this study, when older adults disengaged with goals and were functionally disabled, the rate of depression increased. Research by Chen, Lee, Pethtel, Gutowitz & Kirk (2012) shows that wellbeing is not correlated to age, and that older adults rely on intrinsic rather than extrinsic drivers for motivation and goal pursuit (Chen et al., 2012). In research related to polyarthritis and goals, three goal domains were identified – social, leisure and independent functioning (Arends, Bode, Taal, & van der Laar 2015). Strategies for management were described when attainment of the goal was not possible. This included coping strategies for non-attainment, including adjustment or changing the goal when required. This research found that different methods were preferred for different types of goals. Social goals were adjusted; leisure and functional independence goals were addressed with greater flexibility and thereby maintained and goal disengagement was the least preferred method (Arends et al., 2015). The number and type of goals, adherence and degree of flexibility in approach to goals have implications for health service delivery such as TCP where patient goals are explicitly included.

This chapter appraised the background literature on goal setting theories and the relative benefits, facilitators and barriers, particularly in the health setting. It provided commentary on the chronology of behaviour change theories. In addition, it assessed the evidence for goals with older adults. What it did not do was evaluate the literature that explores the patient experience of goals in the health setting, and the next chapter investigates this.

CHAPTER 3 SYSTEMATIC REVIEW

This previous chapter appraised the literature on health behaviour change through goal setting and the effects of goals with older adults. Despite the depth of literature on goals in rehabilitation, and the importance of functional maintenance goals for older adults (Ebner, Freund & Baltes, 2006), there is limited literature exploring older patients' perceptions and experiences of goal setting and attainment in health services.

This systematic review "Older adults' perceptions and experiences of goal setting and attainment in health services" aims to identify the person's own perspectives of goal setting and pursuit in the health setting. The review is registered in the International prospective register of systematic reviews (PROSPERO) (ID: CRD42017064382).

Methods

Inclusion and exclusion criteria

Types of studies: Studies were included if they: were published or unpublished primary research articles qualitative or quantitative design and examined experiences and/or perceptions of goal setting, attainment or pursuit, within the health context, of adults aged 65 years and older. Studies were excluded if they were not written in English, described a health professional or carer perspective rather than the patient's, or when the goal set was not a personal goal (e.g. for a treatment). Where research described different age ranges, staff member or carer views, the article was included if data could be extracted for those participants aged 65 years and over.

Search strategy and selection of included articles

A search of CINAHL, Medline, SCOPUS, PubMed, PsycInfo, Ageline and EmCare databases from 1966 to 29 May 2018 was conducted with assistance from an expert librarian. Keywords for searching were based on three themes: patient goals, including setting, pursuit and attainment; older adults; and patient experience or perception. The detailed search strategy for Medline is presented in Appendix 1. The search terms were adapted for each database.

Data collection and analysis

The primary author (NB) reviewed all titles identified for relevance, applying the inclusion and exclusion criteria. Three additional independent reviewers (SG, SL, SJG) each completed one third of identified titles and discrepancies were resolved through discussion or through third member mediation. Papers identified as potentially relevant were subjected to abstract review and two members of the team (NB, SG) reviewed each abstract against inclusion and exclusion criteria with the full article retrieved for those deemed relevant. Consensus on those to be included was made through discussion and discrepancies resolved through a third party. In addition, reference lists were screened from the acquired papers and systematic reviews identified through this search. Selection of articles against the inclusion criteria and differences of opinion between first and second reviewer were resolved by discussion or by involving a third reviewer.

Critical appraisal

Evaluation of the quality of the studies was measured with the Leeds Mixed Methods (Long, Godfrey, Randall, Brettle & Grant, 2002) or CASP qualitative (CASP, 2016) critical appraisal tools by two independent reviewers: the primary researcher appraised all and the three other researcher appraised one third each. These tools assessed article quality regarding the study aims, research design, literature reviewed, research design, sampling and recruitment strategies, data collection, potential for bias, analytical rigour, descriptive clarity, and overall rigour. Rigour consists of the three components of trustworthiness: credibility, i.e. true representation of the phenomenon under study; dependability, i.e. clarity of description for data collection methods, analysis and interpretation to evaluate repeatability; and transferability, i.e. results that can be transferred to other populations or settings.

Data extraction

The primary author (NB) extracted all direct participant quotes from selected papers to collate the data and an independent reviewer (SG) checked them for accuracy and completeness. Differences were resolved through discussion or by a third reviewer when required. The systematic interpretive process of analyzing the included papers followed metasynthesis procedures outlined by Sandelowski and Barroso (2006). The aim was to identify new findings beyond the original studies and a systematic approach was applied. Initially, concepts relevant to the research question “what are the lived experiences of older adults and staff in goal setting?” were identified within each paper. The second stage grouped words, sentences or quotes relevant to this question into common themes and concepts. Two independent reviewers (NB and SG) explored themes and concepts, and compared then reviewed them within and between the selected papers with reflection back to the original work to confirm they reflected the original findings. Participant quotes were extracted from each paper to support the emerging concepts. Themes were compared and discussed against the original works by the authors until agreement was reached about how each of the study findings related to the others. An audit trail was maintained through note-taking and meeting minutes. The metasynthesis of qualitative research studies was completed using NVivo 11 qualitative software (QSR, 2015).

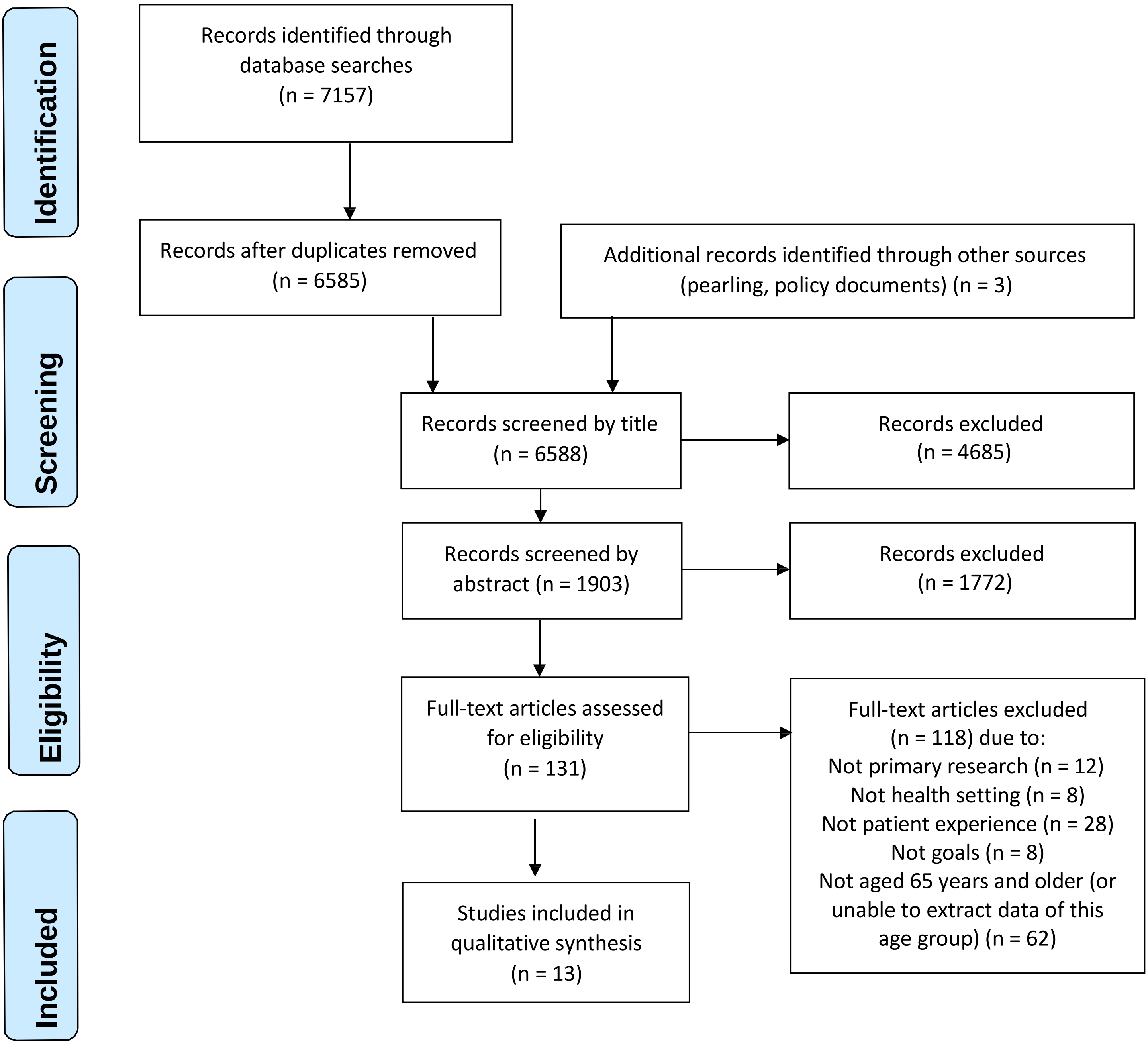
Results

Search results

The search of seven databases identified 7157 titles and 572 duplicate titles were discarded. Of the remaining 6585, 157 were not in English, 321 were not related to health or the health system, 2785 were not reporting patient goals, 771 involved participants less than 65 years, 437 did not describe the patient’s experience and 214 were not primary research. A total of 131 full text articles were assessed against eligibility criteria and a final 13 papers were deemed eligible for full analysis. Figure 1 shows the PRISMA (Moher et al., 2015) flow chart summarizing the search and study selection process.

Figure 1: Prisma flow diagram

PRISMA 2009 Flow Diagram



Characteristics of included studies

There were n = 732 participants (age range 65-100 years, mean age 78 years; 64% female) included in the 13 studies; two mixed methods studies (Melville et al., 2002; Saajanaho et al., 2016) and 11 qualitative studies (Brown et al., 2014; Coylewright, Palmer, O'Neill, Robb, & Fried, 2016; Efraimsson, Sandman, & Rasmussen, 2006; Gorawara-Bhat, Huang & Chin, 2008; Hjelle, Tuntland, Førland, & Alvsvåg, 2017; Huang, Gorawara-Bhat, & Chin, 2005; Kuluski et al., 2013; Pikkarainen, Vähäsantanen, Paloniemi, & Eteläpelto, 2018; Schellinger et al., 2018; Schulman-Green et al., 2006; Wressle, Oberg, & Henriksson, 1999)

Studies were conducted internationally, including the United States of America (Coylewright et al., 2016; Gorawara-Bhat et al., 2008; Huang et al., 2005; Melville et al., 2002; Schellinger et al., 2018; Schulman-Green et al., 2006); Sweden (Efraimsson et al., 2006 and Wressle et al., 1999); Finland (Pikkarainen et al., 2018; Saajanaho et al., 2016); Norway (Hjelle et al., 2017); Canada (Kuluski et al., 2013); and New Zealand (Brown et al., 2014) (Table 1). Settings varied and included acute hospitals (Coylewright et al., 2016; Efraimsson et al., 2006), rehabilitation services (Brown et al., 201; Melville et al., 2002; Wressle et al., 1999); outpatients (Gorawara-Bhat et al., 2008; Huang et al., 2005) and community settings (Hjelle et al., 2017; Kuluski et al., 2013; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schellinger et al., 2018; Schulman-Green et al., 2006). Participants in the studies by Brown et al., 2014; Gorawara-Bhat et al., 2008; Hjelle et al., 2017; Pikkarainen et al., 2018 and Schellinger et al., 2018 were identified as part of larger studies where inclusion criteria and consent were implied. Nine of the 13 studies stated clear inclusion criteria (Coylewright et al., 2016; Efraimsson et al., 2006; Huang et al., 2005; Kuluski et al., 2013; Melville et al., 2002; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schulman-Green et al., 2006; Wressle et al., 1999) with the remaining four studies describing inclusion pertaining to part of a larger or other study (Brown, et al., 2014; Gorawara-Bhat et al., 2008; Hjelle et al., 2017; Schellinger et al., 2018). Exclusion criteria were explicitly stated for cognitive or communication difficulties (Brown et al., 2014) and cognitive difficulties or living in a care home (Huang et al., 2005).

Sample sizes and data collection methods

The studies mainly chose purposive sampling, with sample size ranging from four older adults (of ten participants) (Brown et al., 2014) to 205 (Saajanaho et al., 2016). Data collection was primarily via interviews (Brown et al., 2014; Efraimsson et al., 2006; Gorawara-Bhat et al; 2008; Hjelle et al., 2017; Huang et al., 2005; Kuluski et al., 2013; Wressle et al., 1999) or questionnaires (Saajanaho et al., 2016; Schulman-Green et al., 2006) or a combination of both (Coylewright et al., 2016; Melville et al., 2002). Pikkarainen et al., (2018) used non-participant observation and Schellinger et al., (2018) analyzed the data from electronic medical records that had documented direct patient quotes or patient validated statements. The papers collectively depicted a longitudinal journey through the health system, from the acute hospital setting (Coylewright et al., 2016; Efraimsson et al., 2006) through sub-acute and rehabilitation (Brown et al., 2014; Melville et al., 2002; Pikkarainen et al., 2018; Wressle et al., 1999), outpatients (Huang et al., 2005; Gorawara-Bhat et al., 2008; Kuluski et al., 2013) and into the community (Hjelle et al., 2017; Saajanaho et al., 2016; Schellinger et al., 2018; Schulman-Green et al., 2006).

Table 1: *Characteristics of included studies*

Author (year)	**Country**	**Patients aged 65 years and over (n =)**	**Setting**
Brown et al., (2014)	New Zealand	4 (of 10 participants)	Rehabilitation hospital
Coylewright et al., (2016)	USA	46	Hospital
Efraimsson et al., (2006)	Sweden	7	Hospital
Gorawara-Bhat et al., (2008)	USA	28	Out-patients
Hjelle et al., (2017)	Norway	7 (of 8 participants)	Community
Huang et al., (2005)	USA	28	Out-patients
Kuluski et al., (2013)	Canada	28	Community
Melville et al., (2002)	USA	30	Hospital
Pikkarainen et al., (2018)	Finland	38	Community
Saajanaho et al., (2016)	Finland	205	Community
Schellinger et al., (2018)	USA	160	Community
Schulman-Green et al., (2006)	USA	142	Community
Wressle et al., (1999)	Sweden	8	Hospital

Quality

Table 2 shows the quality appraisal of the included studies. All papers stated a clear purpose and methodology appropriate to address the aims of the study. All but one study (Wressle et al., 1999) used qualitative research designs. The methodology described by Wressle et al. (1999) was not clearly defined, and this paper did not provide details of recruitment strategy, consent processes, ethical approvals or patient confidentiality (Wressle et al., 1999) whereas all the other papers did.

Trustworthiness in the papers varied. Credibility was assessed as high for most papers due to the presence of literature reviews, explicit methodology, use of patient quotes to describe the phenomena under investigation, and data analysis methods using triangulation, member checking or third party involvement. Wressle et al. (1999) did not provide detail for these processes. Dependability was high for most papers (Efraimsson et al., 2006, Gorawara-Bhat et al., 2008, Huang et al., 2005, Kuluski et al., 2013, Melville et al., 2002, Pikkarainen et al., 2018, Saajanaho et al. 2016, Schellinger et al., 2018, Schulman-Green et al., 2006), moderate for Brown et al., 2014; Coylewright et al., 2016 and Hjelle et al., 2017 where the relationship between the researcher and participants was not clear, and poor for Wressle et al. (1999) where there was no description of research rigor or participants who declined to be involved or for what reason. Transferability across studies was considered low due to the heterogeneity of patient groups, small sample sizes and settings. Confidence in the evidence of the selected papers was considered according to the CERQual protocol (Lewin et al., 2018) that has four components: methodological limitations regarding the design or conduct of the included studies; coherence, which is the fit of data to the review findings; adequacy, which measures richness of the data; and relevance, which measures the applicability of findings to the context. The methodology of the selected papers aligns with columns 1-6 in the quality assessment table (Table 2) and identifies overall reasonable quality. Coherence was considered good for all studies providing evidence of the fit of data to the review findings except Melville et al., 2002 and Wressle et al., 1999. All papers except Melville et al., 2002 and Wressle et al., 1999 provided rich data to consider adequacy. All papers were relevant for their chosen field of clinical service.

Table 2: Quality and appraisal table

Author (year)	1. Aims clearly stated	2. Research design appropriat	3. Recruitment strategy appropriate	4. Appropriate data collection	5. Potential bias addresse	6. Ethics	7. Analytical rigour	8. Clear statement of findings	9. Clinical or policy relevance	10. Credibility	11. Dependability	12. Transferability
Brown et al., (2014)	√	√	√	√	x	√	√	√	√	√	√	↓
Coylewright et al., (2016)	√	√	√	√	x	√	√	√	√	√	√	↓
Efraimsson et al., (2006)	√	√	x	x	√	√	√	√	√	√	√	↓
Gorawara-Bhat et al., (2008)	√	√	x	√	x	√	√	√	√	√	√	↓
Hjelle et al., (2017)	√	√	√	√	x	√	√	√	√	√	↓	↓
Huang et al., (2005)	√	√	√	√	√	√	√	√	√	√	√	↓
Kuluski et al., (2013)	√	√	√	√	√	√	√	√	√	√	√	↓
Melville et al., (2002)	√	√	√	√	x	√	x	x	x limited	√	√	↓
Pikkarainen et al., (2018)	√	√	√	√	√	√	√	√	√	√	√	↓
Saajanaho et al., (2016)	√	√	x	√	√	√	√	√	√	√	√	↓
Schellinger et al., (2018)	√	√	√	√	√	√	√	√	√	√	√	↓
Schulman-Green et al., (2006)	√	√	√	√	x	√	√	√	√	√	√	↓
Wressle et al., (1999)	√	x	x	x	x	x	x	x	√	x	x	↓

√ meets quality criteria; x criteria not clear

Two key themes emerged from the data. Participants identified key facilitators and barriers to engaging with goals. The facilitators were either intrinsic (self-determination, ability to look forward, and self-reliance) or extrinsic and provided by family or the staff members. These themes are explored in detail below.

Facilitators to patient involvement in goal setting

Intrinsic facilitators

Participants personal traits, such as determination, level of independence and self-belief reportedly facilitated goal activity whereby participants expressed value in planning goals that enhanced engagement and motivation (Brown et al., 2014, Gorawara-Bhat et al., 2008, Hjelle et al., 2017, Huang et al., 2005, Melville et al., 2002, Pikkarainen et al., 2018, Saajanaho et al., 2016, Wressle et al., 1999). For example

> *"..if you sit down, then you're not going anywhere. You must have the drive to come ahead in life. Goal- setting, has been important and my willpower to exercise*." *(Hjelle et al., 2017, p. 1585)*

Participants described the importance of having an internal locus of control as essential for self-reliance and improved wellbeing (Brown et al., 2014; Coylewright et al., 2016; Gorawara-Bhat et al., 2008, Hjelle et al., 2017; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schulman-Green et al., 2006; Wressle et al., 1999). Participants also noted an additional and essential component of maintaining locus of control was the ability to foresee a 'future self', and identify subsequent desires and wishes in addition to their immediate physiological or functional needs. Participants with a tangible sense of hope were reportedly more engaged in the goal process, even if the future was not tangible (Brown et al., 2014; Coylewright et al., 2016; Efraimsson et al., 2006; Kuluski et al., 2013; Pikkarainen et al., 2018; Saajanaho et al., 2016; Wressle et al., 1999). Schellinger and colleagues reported a participant saying

> *"Never give up hope of staying home" (Schellinger et al., 2018, p. 161)*

Participants' perceived sense of control was stronger if staff members considered them as a unique individual and taken seriously (Brown et al., 2014; Coylewright et al., 2016; Efraimsson et al., 2006; Hjelle et al., 2017; Huang et al., 2005; Kuluski et al., 2013; Melville et al., 2002; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schulman-Green et al., 2006; Wressle et al., 1999). Participants valued the autonomy to decide their own goals (Brown et al., 2014; Coylewright et al., 2016; Efraimsson et al., 2006; Hjelle et al., 2017; Huang et al., 2005; Kuluski et al., 2013; Melville et al., 2002; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schulman-Green et al., 2006; Wressle et al., 1999), including incorporating global or holistic goals (Hjelle et al., 2017; Huang et al., 2005; Schellinger et al., 2018) to return to 'normal' (Gorawara-Bhat et al., 2008; Kuluski et al., 2013; Melville et al., 2002; Pikkarainen et al., 2018; Schellinger et al., 2018; Schulman-Green et al., 2006). Goal pursuit and attainment was facilitated when functional goals were incorporated as part of a bigger life or global goal. Participants' self-reliance and motivation influenced their level of confidence in, trust of and reliance on staff members for goal setting and participation in activities related to their health outcomes (Brown et al., 2014; Efraimsson et al., 2006; Gorawara-Bhat et al., 2008; Hjelle et al., 2017; Huang et al., 2005; Melville et al., 2002; Pikkarainen et al., 2018; Schulman-Green et al., 2006; Wressle et al., 1999).

Participant reports suggested that self-confidence was associated with their degree of dependence and ability to self-care (Efraimsson et al., 2006; Gorawara-Bhat et al., 2008; Melville et al., 2002; Saajanaho et al., 2016; Schulman-Green et al., 2006; Wressle et al., 1999), and perceived wellness (Pikkarainen et al., 2018). Other participants noted it was important to celebrate the small gains as part of the bigger picture (Brown et al., 2014; Hjelle et al., 2017; Melville et al., 2002; Pikkarainen et al., 2018; Saajanaho et al., 2016; Schulman-Green et al., 2006). Brown and colleagues (2014) reported these small gains, which may not be reported in the daily medical records by staff:

> "*I just took it day by day and I sort of set myself certain things to do ... if I felt I got through those fairly good, easily, I just took another step forward." (Brown et al., 2014, p. 1023).*

Extrinsic facilitators

Participants reported extrinsic facilitators to goal setting included staff members, family and friends. Staff expertise regarding the health condition, prognosis and treatment options was identified by participants as important to accurate and meaningful goal setting (Brown et al., 2014; Hjelle et al., 2017; Pikkarainen et al., 2018).

> *"I will always do what they recommend. I have great faith in them. I believe in them and I do what I'm told to do." (Schulman-Green et al., 2006 p.147)*

This was particularly so when explicit language was used, so that shared decision making occurred (Coylewright et al., 2016, Efraimsson et al., 2006, Hjelle et al., 2017; Huang et al., 2005; Melville et al., 2002; Pikkarainen et al., 2018; Schulman-Green et al., 2006). Likewise, participants reported that staff members facilitated goal setting by using a coaching approach, where goals were revisited frequently, goal progression was addressed in a flexible manner and goals included managing complications and future planning (Brown et al., 2014; Gorawara-Bhat et al., 2008; Hjelle et al., 2017; Kuluski et al., 2013; Melville et al., 2002; Saajanaho et al., 2016; Schellinger et al., 2018).This incorporated some broader outcomes such as getting affairs in order and strategies to avoid being a burden on loved ones (Coylewright et al., 2016; Huang et al., 2005, Kuluski et al., 2013; Pikkarainen et al., 2018; Schellinger et al., 2018).

Participants expressed that flexibility in goal setting and pursuit was necessary to address the uncertainty of progress due to fluctuations in clinical, physical or emotional status, or degree or speed of progress. Further, small daily goals were reported to be as important as longer term, future goals. Participants also identified input from staff was necessary for re-evaluation or re-definition of goals in scenarios such as not achieving goals, making slower progress than expected, or at transition or discharge. In addition to the intrinsic and extrinsic facilitators, barriers to goal setting were identified in this review.

Barriers

Participant barriers

Barriers to goal setting included participants' reduced ability to discuss goals due to communication or cognitive concerns. Barriers to goal pursuit included patients experiencing pain, reduced ability to self-care sometimes aligned with frailty, and fatigue such as reduced energy or a lack of sleep:

> *"..but (I was) exhausted, exhausted, so exhausted and ... weak and .... tired ..." (Efraimsson et al., 2006, p. 72)*
>
> *"Right now I don't have the energy to do anything. I sleep all the time" (Coylewright et al., 2016, p. 1040)*

Fatigue reduced the energy level required by participants to manage their condition and focus on their goals. Emotional barriers were generated by the unpredictability of the unplanned health event, leading to uncertainty of the future. This was further influenced by the acuity of the condition when the patient was in shock and their primary concern was simply surviving, not setting goals:

> *"goal planning really wasn't a high priority, I was just doing the best that I could" (Brown et al., 2014, p. 1023)*

Regardless of the study setting, some participants identified a degree of helplessness, which was closely linked to a lack of knowledge about diagnosis, progress, or discharge plans, and a reliance on the staff members for medical stability or symptom relief:

> "*I feel as if the future is uncertain and I don't know how life will end up. Am I going to be better or remain disabled and in that case how severely?" (Efraimsson et al., 2006, p. 72)*

In contrast some participants felt overwhelmed and disengaged when an excess of information was provided:

> *"And I wondered: 'Why is she (the social worker) asking so much?' and ... 'I am just going home, am I not?', I thought ... So I did not really follow what they were talking about." (Efraimsson et al., 2006, p. 74)*

Other participants described a fear of the unknown, including a potential change in future roles (Wressle et al., 1999) or of becoming a burden on others (Gorawara-Bhat et al., 2008; Huang et al., 2005; Kuluski et al., 2013; Schellinger et al., 2018):

> *"of course, I do not ever want to become a burden to my sons." (Huang et al., 2005, p. 309)*

Stress was frequently noted among participants and was a reported barrier to being able to being able to clearly articulate and act on goals such as managing symptoms:

> *"…I could go blind…I could have an amputee… like, my sister had diabetes. She had (to have) her legs amputated… So I know those things can happen (to me)…" (Gorawara-Bhat et al., 2008, p. 413)*

System barriers

Organizational barriers included the time taken for goal discussions, and timing of the goal discussion within the patient's health journey and life course. Goal setting language that was unfamiliar to the patient was noted as a barrier. Terminology was varied in the selected articles and changed between health goals (Schulman-Green et al., 2006), care goals (Coylewright et al., 2016; Kuluski et al., 2013; Schellinger et al., 2018), healthcare goals (Huang et al., 2005; Gorawara-Bhat et al., 2008); life goals (Schulman-Green et al., 2006); patient goals (Brown et al., 2014); personal goals (Efraimsson et al., 2006; Hjelle et al., 2017; Saajanaho et al., 2016), rehabilitation goals (Pikkarainen et al., 2018), treatment goals (Wressle et al., 1999) and tasks (Melville et al., 2002). Additionally, both too little (Gorawara-Bhat et al., 2008; Hjelle et al., 2017) and too much information (Efraimsson et al., 2006) were identified as barriers.

> *"'Why is she (the social worker) asking so much?' and…'I am just going home, am I not?', I thought…So I did not really follow what they were talking about." (Efraimsson et al., 2006, p. 74)*

One presumption by staff was that all patient goals were the same, i.e. to improve function (Schulman-Green et al., 2006), resulting in patients not being considered as individuals with unique goal preferences. The final barrier identified described the patient unwilling to take on new information regarding their goals while in the health system (Melville et al., 2002; Pikkarainen et al., 2018; Wressle et al., 1999) thereby not engaging with the goal process:

> *'I have heard this already … I know this' (Pikkarainen et al., 2018, p. 7)*

Discussion

This systematic review has synthesized studies describing older patients' experiences of goal setting and attainment in the context of the health system. Despite the wealth of evidence for patient goals in rehabilitation (Levack, Wetherall et al., 2015) and chronic disease self-management (Lawn & Schoo, 2010), there is a relative lack of research investigating purely older adults' experiences of health related goal setting with 13 studies included in this review. The qualitative nature of describing experiences resulted in qualitative or mixed methods studies being selected. Consistent findings were barriers and facilitators to patient engagement in goal setting and attainment and how communication occurred to enhance or deter effectiveness. Patients needed to engage with goal setting at all stages of their health journey, from the acute setting, through rehabilitation and into the community. Barriers to effective goal setting and attainment included the physical and emotional factors associated with illness and hospital admission, such as feeling fatigued. System barriers encompassed the lack of time for staff members to establish goals and the patients' lack of familiarity with goal language. Patients reported feeling less in control in the high acuity situation when their focus was on survival. When investigating goals with older adults, Huijg (2016) identified that goal concepts were principally around ageing successfully (Huijg et al., 2016). This body of research identified an association between the perceived health and the type of goal chosen by older people. For example, when the older adult was medically unwell, their goals trended toward personal recovery, whilst those older adults who were medically well were more likely to engage in activity or leisure goals. This review supports these findings and could assist staff members to facilitate goal setting with patients across their health journey.

People with lower health resources have been shown to be more socially isolated than those with good resource access (Saajanaho et al., 2016). When associated with self-preservation, there is a reduction in self-rated health, reduced meaning to life, more dissatisfaction and a negative expectation for the future (Lapierre, Bouffard & Bastin, 1997). This aligns with the study findings regarding self-determination in this review. Older adults are more likely to be motivated to engage with community programs and goals if they are well-informed of the potential benefits and believe the program will assist (Hawkins, Wells, Hommer, 2014) which aligns with information provided by the staff that was found in this review.

Tools have been trialed by staff members to make participant goal identification easier, such as the two- step process for frail elderly people in the community by Robben et al., (2015) and the TARGET tool (Parsons & Parsons, 2012). Quantitative measures like these provide a structured approach to assist staff members determine what is most important to older participants. The International Classification of Function (ICF) model (WHO, 2001), provides a model that staff members can use to identify 'SMART' (specific, measurable, achievable, relevant and time- bound) goals that help patients identify tangible goals and simultaneously produce a quantifiable outcome measure to match external pressures of discharge planning and length of stay (Levack et al., 2011; Rosewilliam et al., 2011).

Another finding of this review is that the factors important to the participant were not necessarily important to the staff member and vice versa, and this was reinforced by the different terminology associated with goals. Participant goals were broader than the context of a single service and more holistic than treatment goals, health goals, or care goals. When participants engaged well with goals, then they were more motivated and engaged with the treatment and self-management. The clinical implications of this are to provide consistent goal language, facilitate goal identification using the patient's words and provide regular reviews of goals to support the patient with any modification, change in direction or progression of goals.

Limitations

The heterogeneity of settings, data collection and analysis methods of the included articles reduces the strength of the findings by not providing evidence that is transferable outside of the reported settings. In addition, this review is limited in that it investigated participants' perceptions and experiences of their goals in the health setting without cross-referencing to the experiences of perceptions of carers or staff members.

Conclusion

Understanding goal setting in relation to the timing of a health event in a patient's life will assist staff members to facilitate goal identification and pursuit. Using consistent 'patient goal' terminology puts the patient at the centre of the conversation, assists the patient to articulate what is important to them both now and into the future, avoids confusion with alternate terms that imply different motives, and provides the platform to assist the patient to work toward meeting those goals.

Further research is required to investigate the influences of socio-economic status or cultural background for older adults with health-related goals. Further, this population of older adults are often involved with goals only after an acute event, and further research is warranted to investigate the effects of fatigue and cognitive deficits with health goals.

The findings in this review reinforced investigation of this research to the patient centeredness of goal setting and choosing phenomenology as the methodology which is detailed in the next chapter. This in turn promoted the creation of the research question "what is the lived experience of older patients participating in goal setting and pursuit at TCP?" The language and communication results of this review also assisted development of the interview questions which were structured to explore the patient experience according to perceptions and understanding, processes and the outcomes of goals in TCP.

CHAPTER 4 METHODOLOGY

Introduction

This chapter describes and justifies the methodology chosen for this research, with the question “What are the client and staff experiences of goal setting and pursuit in TCP?”, including the main philosophical influences of hermeneutic phenomenology and its relevance to this research.

An investigative approach developed insights into the experiences and perceptions of people undertaking goal setting and pursuit in the TCP setting. This approach was driven by a desire and gap in the literature to understand the client experience and add that to the practitioner’s view of the client experience to create new understanding.

Different approaches were considered for this research question. The plan to explore the client experience did not fit with a case study approach. An ethnographic approach was considered, because it investigates the relationship between culture and behaviour. However, the complexity and depth of client experiences was of more importance than the culture of the service because the intent was to investigate the person-centeredness and meaning of goals for the clients in the service. Grounded theory was considered as it investigates experiences but I wanted to focus on the person-centeredness rather than develop a new model for goal setting and pursuit in TCP.

Theoretical approach: the lived experience

A hermeneutic phenomenological approach was identified as the best approach to explore and reflect on the stories presented to understand the lived experience of goal setting of older adults in TCP. The approach provided an opening for me to immerse in the clients’ experiences and gain a deeper insight and understanding of their world view. Their world view was interpreted by my own consideration of what was discovered through their experiences. The influence of a phenomenological approach was to gain a sense of the lived experience of older adults identifying and pursuing goals in TCP. Bringing an interpretive aspect to the person’s perceptions and disclosures was intended to provide a greater understanding of their experience, what influenced this, and how. The purpose of investigating older adult’s experiences was to provide insights for staff to enhance the person centred approach in TCP.

Hermeneutics and phenomenology

Hermeneutics and phenomenology developed over time with different philosophies evolving, thereby creating new understanding. Phenomenology describes a philosophical approach to understanding a phenomenon, which is described as something that someone consciously experiences (Gill, 2014). Phenomenology is core to qualitative research as it explores the fundamentals of the experience. In research terms, phenomenology is a method to discover the world as it appears to someone as they live and experience it (Gill, 2014). Dowling (2012) describes phenomenology as both a philosophy and an approach to research where the basic principle is to investigate and understand the lived experience (Dowling & Cooney, 2012). This is mirrored by van Manen (1990) who suggested that anything that presents itself to consciousness is of interest to phenomenology (van Manen, 1990).

Hermeneutics is an approach to interpretation of phenomena, or the ‘theory and practice of interpretation’ (van Manen, 1990). The word hermeneutic comes from the Greek god Hermes, the mythological winged messenger and interpreter for the gods on Mt Olympus in ancient Greece. Hermes communicated messages between the gods and mortals and had the ability to translate the unknowable into language and form that humans could understand. Hermeneutics flourished in the 17th century as a means to interpret the previously mystical biblical texts (Dowling, 2004). The following describes the approach required to answer the research question by investigating the phenomenological history and development of hermeneutic phenomenology.

Development of phenomenological approaches

Husserl, Heidegger, Gadamer

Philosophy integrates ontology, the study of being, and epistemology, the study of knowing (Cohen & Omery, 1994). Husserl (1859-1938) was the first philosopher to describe phenomenology as a means to understand the lived experience, to investigate the ‘essence’ of the experience. Husserl proposed that the meaning of a phenomenon occurs only when a person experiences it and therefore there is a clear connection, but also clear distinction, between the experience and the person experiencing it (Dowling & Cooney, 2012). Husserl believed it was possible to separate and discount, or bracket, what the observer knows and feels about an experience from the experiences of the subject under investigation. This permits the observer to identify and describe the experiences of the subject in an unemotional and objective manner. The process of bracketing out preconceptions defines the Husserlian approach as descriptive phenomenology and was the first attempt to describe objectively the lived experience (Dowling, 2007).

This basis developed a framework for psychology and research, where the researcher’s initial task was to identify and acknowledge their understanding and experience of a phenomenon so it remained distinct from the experience and the words of the research subject. Criticisms developed as philosophers challenged the concept of a single ‘essence’ of experience, suggesting that experiences are fluid and dynamic, and therefore constantly changing (Dowling, 2007).

Martin Heidegger (1889-1976) was a student of Husserl and challenged the descriptive approach of the experience to consider deeper understanding of the meaning of the experience. Heidegger suggested it was not possible for the researchers to separate their own interpretation from an objective description and developed further the hermeneutic methodology approach, the method of interpretation (Gill, 2014). This changed the focus from Husserl's descriptive to new explorative and interpretive analysis. Whilst Husserl's focus was on the epistemological approach by maintaining objectivity, Heidegger's focus was ontological, studying the 'human experience of being' (Gill, 2014 p.120).

Hans-Georg Gadamer (1900-2002) was a student of both Husserl and Heidegger. His theories built on the principles of Husserl and Heidegger's work for more practical application using language as the common denominator for both understanding and interpreting the experiences (Laverty, 2003). Gadamer described four concepts: prejudice; fusion of horizons; the hermeneutic circle; and, play (Gadamer, 1975). He extended the beliefs of Heidegger to suggest that all understanding is related to language and tradition.

Prejudice

For Gadamer, the concept of prejudice is that judgement is made prior to all facts being known. In this context, prejudice is a description of the degree of understanding or awareness of a phenomenon, prior to exposure. Prejudice, for example, would influence the language used to create questions for research participants (Gadamer, 1975).

Fusion of Horizons

Gadamer described understanding as a constantly evolving process. He described a 'fusion of horizons' between the understanding of the researcher and the meaning of the text. In this context, a horizon is possibly a metaphor for what is seen from a particular viewpoint and could be close or distant according to the person's perception. By questioning beliefs and experiences, these horizons may merge or expand to show new areas previously not viewed (Laverty, 2003).

Hermeneutic circle

Interpretation of phenomena is described as circular rather than linear, with no particular start or finish, because it is an interpretation of the experience within the life of the subject. The interpretation constantly evolves in a vibrant way, with stories being part of a continuum rather than being discrete. In this way, stories are captured as part of the entire phenomenon under investigation rather than in isolation, and the whole can be understood by study of the part, and the part understood by study of the whole.

Play

Gadamer avoided subjective or objective interpretation and preferred to consider himself as a player within the analogy of a game. Each player has their role in the game but is simultaneously immersed in the game as a whole. This approach provides opportunities to move freely around the text and the hermeneutic circle, to view distinct parts or the whole according to the fit at the time. (Gadamer, 1975)

Lastly, the Dutch or Utrecht movement was developed from a pedagogical perspective by Max van Manen (born 1942) (Gill, 2014). His approach pools both descriptive and interpretive approaches to phenomenology, identifying phenomenology as a practical and reflective method rather than philosophical approach. His method emphasizes the importance of language as central to all human connectivity and that research carried out in this way is driven by a deep desire to understand the phenomenon. He suggests a six-step approach that is to remain flexible rather than fixed. The first step is for researchers to become acquainted with the phenomenon being researched. The second step is to investigate the experience by gathering descriptions of the experiences through observation or interviews. The third step is to reflect on the necessary themes that identify the phenomenon under study. Next is the fourth step of describing the phenomena, through writing and re-writing. The fifth step is relating to the phenomenon and the final sixth step is balancing the context by considering the parts and the whole to be able to create new meaning. The steps are ordinal; however, there is constant movement forward and back between them when considering the parts, the whole, and the researcher’s prejudice in relation to these (Gadamer, 1975).

His methodology recommends thematic analysis that separates the essential from non-essential findings; that is, those themes that make the phenomenon what it is (essential) and those that can change without affecting the phenomenon (incidental). The findings are then evaluated in a reflective and reflexive manner to establish cause and effect, in the context of both drilling down to detail and considering the whole. New findings emerge and inform new meaning (Gill, 2014).

Researcher’s perspective

Research following a hermeneutic phenomenological approach can increase the understanding of actual experiences of the phenomenon. It lends itself well to application in the health professions, where researchers can use the methodology to dive deep into the experiences of the research participants. This provides the opportunity for clinicians and policy makers to view the world from the participants' perspective and use their own understandings to complement new findings and deduce meaning to improve practice or policy.

As a clinician with over 30 years' experience in hospital and community settings, I have experienced first-hand the attempts to provide person centred therapy and treatment whilst simultaneously experiencing the frustration of processes and systems that do not accommodate them. My preference in this research was to interpret the phenomena rather than just describe them, which indicated more of a Heideggerian phenomenological approach than Husserlian. Older adults' experiences of goals were explored with semi-structured interviews and staff experiences by focus groups.

Van Manen's approach was taken with this investigation into the lived experience of clients and staff. The first step was to turn to a phenomenon of interest and become acquainted with it to make sense of the experience. Having previously worked as a team leader in the TCP service under investigation, I had observed the goal setting process and was curious to investigate if it was truly person centred. This led to the development of the research question: 'what are the lived experiences of older adults and staff in goal setting and pursuit at TCP?' During data analysis, this question was forefront to confirm the analytical methods were appropriate. In order to understand the experiences of older adults in relation to their goals it was necessary to be with them to listen without judgement to their stories and narratives, encouraging them to talk. This was the second step of van Manen's approach; investigating the experience as it is lived. Asking the older adults in TCP to relate their experiences of goal setting illuminated what it meant to them in the broader context of their lives. The three different time points for clients provided a narrative of their experiences over time and how these experiences shaped their views and feelings about goals. Staff explored goals in the context of their daily work routines and practices, relating their own experiences of goals in TCP. The third step, reflecting on essential themes that characterize the phenomenon, was central to identifying the essence of the participants' experiences. This was undertaken by constantly reading and reviewing the transcripts and listening to the audio recordings of the interviews, identifying key phrases to become themes and sub-themes that gave meaning to the phenomenon of older adults' experiences of goal setting and pursuit.

The fourth step, describing the phenomenon through writing and re-writing, was an iterative process. Phenomenology is the discovery of new understanding through consideration of an aspect of the lived experience and application of language to interpret it. The attitudes, thoughts and feelings of the older adult participants are made explicit through themes identified by a constant process of moving between the detail of words within interviews and the larger context of goal setting in health systems. This methodology was also applied to the staff focus group data. Description of how themes were developed is explored in the next chapter.

Step 5, maintaining a strong relation to the phenomenon, was revisited constantly during data analysis and write up of results. Van Manen recommends the researcher keep a strong connection to the phenomenon under study and be constantly aware of the prejudice of pre-knowledge and its influence on interpreting the data.

The final step 6 of balancing the context by considering the parts with the whole was done with writing the discussion chapter. This looked into the detail of results and then stepped back to view how the detail informed the whole picture and vice versa. This aligns with the hermeneutic circle described by Gadamer.

My concerns with the appropriateness of staff focus groups within a phenomenological approach were justified by the opportunity to inspire vigorous discussion in the focus group, and therefore develop new views. This justification is supported in the literature (Bradbury-Jones, Sambrook, & Irvine, 2009).

Summary

This chapter identified the methodology identified for this research project, the background history and development of hermeneutic phenomenology and the application to this piece of research. The following chapter describes the methods undertaken to follow the methodology outlined in this chapter.

CHAPTER 5 METHOD OF QUALITATIVE STUDY

Introduction

The first section of this thesis refers to the person at the core of the research as a ‘patient’ due to their situation in the acute sector, being the recipient of medical and care interventions. As stated previously, the terminology changes to ‘client’ to identify the movement away from the health institute to the community setting. The TCP is a non-acute service and whilst the person is still a recipient of ‘care’, it is a non-medicalized program offering personal support and low intensity therapy.

There are a range of public and private providers operating community and residential TCPs in South Australia. This research was conducted in one venue that offered a residential TCP in metropolitan Adelaide. State Government funded the program that was co-managed by the State health service and private enterprise, the latter providing management services, nursing and care staff; the former providing pharmacy and medical input (geriatric consultation), allied health professional and assistant staff (social work, physiotherapy, occupational therapy, dietetics and speech pathology). Client goals were identified by the TCP liaison officer with the client while they were still in the acute hospital, prior to arrival in TCP.

Research design

This was a prospective qualitative study involving individual semi-structured interviews with 10-15 TCP clients at three time points; admission, discharge and three months after discharge. Interviews were semi-structured with open questions that investigated client perceptions and experiences of goals in TCP throughout the admission and afterwards. Additionally, the perceptions and experiences of staff were sought through focus groups.

The ‘life world’ of clients was investigated by semi-structured interviews that explored experiences, examples and descriptions of their goals in relation to TCP. Questions were identified through review of the literature on goal setting and discussion with clinical colleagues. Discussion with clients included reflection back and clarification between researcher and client to dig deeper. The same questions were asked at each of the three time points to explore changes in perceptions and experiences over time for the same topic. This approach during the in-depth interviews allowed full exploration of each client’s experiences.

The method for gathering data from staff was different and occurred in focus groups rather than interviews. The rationale for this method was to elicit and encourage reflection and discussion among the staff about client goals. This would allow them to discuss their experiences of client goal setting in TCP, what and how goals were created, how goal attainment was measured and how the goals were incorporated into clinical interventions. This hermeneutic phenomenological research followed steps described by van Manen (1990) to capture the experiences of clients and staff of goal setting in the context of TCP.

Ethical approvals

This qualitative study was approved by Southern Adelaide Clinical Human Research Ethics committee (#436.16) and included a site specific approval. Ethical approval was also provided by the private enterprise Clinical Governance Committee, due to private enterprise managing the TCP on the Southern Adelaide Local Health Network (SA Health) site (Appendix 2).

Participants

Eligibility

Eligible clients were aged 65 years of age or over, had been admitted to the Southern Adelaide Local Health Network residential TCP between 1 September and 20 December 2017, and had cognitive and communication ability to participate in an interview in English.

Eligible staff were employed to work in TCP for either the State health or private enterprise company. Staff who represented both the liaison team and residential team were eligible. Volunteer and non-clinical staff were excluded.

Recruitment strategy

Potential client participants were invited via flyer (Appendix 3) or by word of mouth by the TCP site manager, who was employed by the private enterprise and independent of the research. One to three working days after receiving study information, potential client participants were approached by the primary researcher to answer any queries about the research and determine if they were interested in participating. Interested clients were provided with a participant information and consent form (Appendix 4). No consent was sought until queries were answered and clients understood the consent and participation requirements.

Staff who worked in TCP at the time of the study and were employed by either SA Health or private enterprise, were invited to participate. Invitation was by word of mouth or by flyer (Appendix 3) by the private enterprise site manager or the SA Health Transition Services Manager, both of whom were independent of the research. The two site managers disseminated the flyer to staff at their respective staff meetings and provided permission for the staff to attend during work hours. The primary researcher was invited to attend staff meetings to explain and answer any questions about the research. Staff were then invited to register their interest for participation via a sign-up sheet (Appendix 5) that offered focus groups on different days and times to accommodate part-time staff. The primary researcher’s contact details were included to accommodate queries or registration of interest in private. Staff participants were provided with a participant information and consent form (Appendix 6) that explained that their participation was for up to one hour for one focus group only and that data would be de-identified. When three or more participants volunteered to represent the staff on the days offered, the focus groups were arranged and confirmed. Recruitment commenced on 5 September 2017, the day following receipt of ethical approvals. The TCP site manager was provided with flyers to distribute to all clients admitted on that and subsequent days until client recruitment ceased on 30 October 2017.

Both groups of participants, clients and staff, formed a convenience sample with: the clients admitted between the two above dates approached and provided with an opportunity to participate; staff participants as a volunteer cohort of employees who were both interested in and available to share their thoughts and experiences of goals within the context of TCP.

Consent process

After having all queries and concerns answered, informed consent was obtained from clients and a mutually convenient time arranged for the first interview. The consent process included confirmation from the participant that they agreed to be interviewed at the three time points. Clients who were not interested in participating, had cognitive or communication difficulties, or were unable to explain back to the researcher what their involvement in the research project entailed, were excluded from the research project.

Staff interested in participating were invited to attend a focus group. Informed consent was provided by staff at the commencement of the focus group after all queries had been answered satisfactorily. De-identified demographic data was collected at the same time (Appendix 7).

Data collection

Interviews and focus groups were conducted by the primary researcher. Client participants were interviewed at admission and discharge in the privacy of their own rooms in TCP to provide confidentiality, encourage free speech and allow full exploration of concepts and ideas in the comfort of their own space. All rooms in this residential TCP are single rooms. Client participants consented to their interview being audio-recorded and for the researcher to take notes, which were read back at the end of the interview for clarification and confirmation of accuracy. At their first semi-structured interview, client participants provided baseline demographic data and details of their hospital journey that led to the TCP admission at that point in time, including to which hospitals they had been admitted, for what reasons, and for how long.

An interview schedule (see Appendix 8) consisting of open-ended questions was utilised to guide the interview (Patton, 1990) and explored three main context area. The first context area explored client perceptions, understanding and meaning of goal setting and goal attainment, and included what goal setting meant to the client, how the goals for TCP were identified and created, what the client got out of setting the goals, and some of the benefits and challenges associated with goals in TCP. The second context area explored client perceptions of processes involved with goals in TCP, such as how the goals affected the client's stay or influenced their daily activities, what the client was doing to work toward achieving their goals and how this was measured, or if the goals were revisited at any point in time and if so, how and why. The third context area explored the outcomes of goal setting such as why the client had goals, what relevance their goals had, how the goals informed what the client did in the program, any enablers or barriers to achieving their goals, whether they were still working towards any goals or if any had been achieved and if the latter, were they the right ones to choose. The same questions were asked at the three different time points for clients – at admission, on discharge and three months after discharge from TCP. At the end of the first interview, the client participants consented to be contacted for a follow up interview as close as practicable to the discharge date, once that date was identified. The same process of confirming consent was followed and agreed to at the discharge interview for the three-month follow-up interview, regardless of discharge destination. Three-month follow-up interviews were conducted at the client's home. For some clients, this was their original home and for other clients it was a new home in a residential care facility.

Staff focus groups were conducted in closed meeting rooms to ensure the group's privacy and confidentiality and to encourage free speech. Focus group activity was chosen as a means to encourage discussion between staff and gain understanding and interpretation of the group's perspectives on client goals through the group interaction that would not be possible with questionnaires (Liamputtong, 2011; Ritchie, Lewis, Nicholls & Ormston, 2013). Each staff member attended one focus group only. Staff participants gave consent for the discussions to be audio-recorded and provided baseline demographic data at the start of the focus groups. The same interview guide was used to explore staff perceptions and (Appendix 8) experiences of goal setting with their clients.

Data analysis

Initial goal discussions had commenced prior to admission to TCP when the TCP liaison staff met the client in the acute setting. This occurred to ensure the client had a list of goals ready to address on arrival in TCP. Liaison staff in the acute setting assisted the client to define their goals which were written down in functional language such as 'shower myself independently' or 'walk safely by myself with walker'. These goals were documented and provided as part of the referral from the acute hospital to the Transition Care Program. The goals identified on the admission paperwork by the liaison staff created the starting place for TCP residential staff to be involved.

During the interviews, the participants talked about their experiences of the journey through the acute and subacute hospitals that had brought them to this point of admission to TCP, and how these experiences and feelings related to pursuing goals in TCP. Each interview and focus group was transcribed verbatim and entered into NVivo 11 (NVivo, 2015) for data analysis and coding. Data analysis of each interview and focus group followed the steps of van Manen: step 3 was initial reflection of themes, step 4 described the phenomenon, step 5 related to the phenomenon and step 6 balanced the context.

Transcripts of client interviews were coded for the three separate time points, and for each of the staff focus groups. As per van Manen's third step where reflections on the lived experience occur, an initial client admission transcript was coded independently by three members of the research team. Each identified key phrases independently. Tentative concepts were discussed between the three researchers (NB, SG, SL) and related back to the research question for relevance and true depiction of the phenomenon being studied. This process provided the first level of coding for the first admission interview which was then added to and expanded as new admission interviews were transcribed. This process constantly evolved when adding transcriptions for subsequent client interviews and staff focus groups. The primary researcher re-read transcripts and re-listened to audio recordings to identify nuances and inflections in speech that added depth to meaning, consistent with the third stage of van Manen's approach. Constant checking within the transcript and between researchers ensured that the themes reflected the experiences, thoughts and feelings of the participants in the context of goal setting and pursuit in TCP.

Writing and re-writing, as per van Manen's fourth stage, permitted new discoveries of the lived experience for participants. The primary researcher was constantly aware of my bias due to my personal experience of the service and acknowledged this in the development of themes for each of the time points of client interviews and staff focus groups. This was moderated by the independent coding from two other members (SG, SL) of the research team. The three coders discussed and reviewed all themes in relation to the whole picture and reached consensus with discussion.

Maintaining a strong relation to the phenomenon under investigation, step five of van Manen and in this case, client centeredness of goal identification and pursuit in TCP was essential and revisited constantly as writing occurred. Van Manen's step 6 was followed by considering the overarching themes in alignment with the detail within them, and relaying everything back to the phenomenon under investigation.

CHAPTER 6 RESULTS

Overview

The results are presented in a narrative format, describing the clients' goals as part of their chronological journey from admission to TCP and back into the community. Client experiences and perceptions are explored over the three different time points and present a chronological story. Staff results provide a different perspective and are reported after the client results. For ease of reading, client participants are referred to as 'participants' and staff participants as 'staff'. Quotes are provided to demonstrate the themes and use unique identifiers; participant clients (P) or staff (S), each with a confidential identifier number, participant gender and age at admission to TCP (e.g. P3, f, 97) and time point of interview - admission (T1), discharge (T2) or three months after discharge (T3). All interviews at T1 and T2 were completed on-site at the residential TCP and T3 interviews were completed in the community.

The Participants

Of the 51 older adults admitted to the TCP between 5 September and 30 October 2017, five (10%) had communication or cognitive barriers that made them ineligible.

Of the 46 eligible adults, eight were not available (four (9%) were not in the room or asleep and four (9%) were transferred back to the acute hospital between admission day and researcher approach time); thirteen (28%) stated they were not interested or did not feel like participating in research. In addition, five (11%) declined by saying it was simply "too much"; two (4%) stated they were "too tired"; one client (2%) reported feeling "too unwell", and four other clients (9%) dismissed the notion of participating in goal setting discussions because they were "too old" even though it had been a requirement to identify goals to be admitted to the program. The remaining 13 clients who chose to engage cited reasons such as "it gave them something to do" or "they liked to have a chat."

Table 3 describes the participant demographics of clients at the three different time points.

Table 3: Participant demographics:

	Admission interview	**Discharge interview**	**3 months interview**
Participants Numbers	13	10	9
Age range in years (mean) [Standard Deviation]	68-97 (84.3) [9.7]	68-97 (84.0) [10.4]	68-97 (84.4) [19.4]
Gender (% female)	54	50	44
Days since admission to TCP (mean) [SD]	0-10 (4) [3.9]	20-79 (45) [16.7]	121-221 (171) [33.3]

Thirteen participants aged between 68 and 97 years (mean = 84.3 years ± 9.7) consented to discuss their goals on admission (T1). All participants were Caucasian; seven born in Australia, four originally from United Kingdom, one from Canada and one from Germany. The reasons for admission to the TCP were reduced physical functioning due to medical illness (respiratory disease n = 2, infection n = 1, cancer n = 1), fall sustaining fracture (n = 4), fall without subsequent fracture (n = 4), or post-surgical deconditioning (n = 1). Participants had spent between 11 and 57 days (mean 32.7, ± 14.0 days) in the acute hospital system, and in some cases subacute rehabilitation or Geriatric Evaluation and Management units, before being admitted to TCP. All were recruited to this project within 10 days of admission to TCP. All interviews were conducted at a time convenient to the client and in the privacy of the person's room at TCP, where all rooms are single.

At discharge (T2), three of the original 13 participants were lost to follow up – one had been discharged and was not contactable, one declined further interview at discharge saying it was too much for them now they had just arrived back home, and one participant was unwell, confabulating and unable to hold a coherent conversation, so was referred back to the medical team for acute medical management. This provided ten participants for interviews at discharge, which were again conducted in the privacy of the participant's room at TCP the day before discharge. Of these ten, seven participants were due to be discharged back to their own home, and the remaining three participants were to be discharged to a new home at a residential care facility (RCF). The mean admission time in TCP was 6.5 weeks (± 16.7days).

At three months post-discharge (T3), nine of the ten participants who had provided discharge interviews were available and agreed to participate in the follow up interviews (one participant had died since the discharge interviews). Participant interviews occurred in the privacy of the participant's own home at a time convenient to them. The discussion took place between 11 and 26 weeks after discharge from TCP. The variability in follow up time was due to the either participants not responding to follow up contact calls made by the researcher, or the researcher not being available to conduct the interviews. One participant who was interviewed almost 6 months later had been readmitted twice to hospital since discharge from TCP, which was why she had not previously responded to the follow up phone call.

This narrative describes the client goal journey from admission, through discharge to three months follow up after TCP. The narrative explores experiences of how participants identified and addressed these goals. It also explores how participants felt through this experience, and how progress was measured and recognized at each of the time points.

Participants identified their primary drivers of being in TCP were 'returning home' and 'getting back to normal'. These two goals were most important to participants and became the first two themes to emerge from the participant data. Home and normal were consistent at each time point although the experience or perceptions differed between participants and time points. The third major theme to emerge from the interviews was fatigue. Fatigue overwhelmed participants and affected their thoughts, behaviours and experiences. The final theme to emerge was the experiences of support and the influence that support provided over the three time points.

Discharge to home was the primary goal of every participant. The reason for admission to TCP was to have the additional time and the restorative care provision to go home. For participants, the concept of home changed over the journey through TCP and into the community, depending on the circumstances of the individual, how their function changed and what services were necessary to support them to function.

Theme 1 Home

Everyone coming into TCP was aiming for home and home was the main driver for all the clients to engage in goal setting and pursuit in TCP:

"My main goals is to get better… important for me to get home, into my own place" (P1, f, 96, T1)

Home encapsulated the security and familiarity that was part of the person's identity:

"It's a personal need to be home... when I walk in that door, the house welcomes me" (P7, m, 72, T1)

"I want to be home in my own bed" (P9, m, 83, T1)

"My main goal is to get us back home and be well again" (P10, m, 82, T1)

Some participants knew they wanted to be at home but had not considered the behavioural steps to achieve those goals, other than in broad terms:

"To come to an agreement about what I think for the future, and work towards gaining that" (P5, m, 68, T1)

For these participants, home provided the identity, sanctuary and familiarity that were currently missing in TCP. Home meant being in their own place with their own things, doing the activities they wanted to do, in the time that they wanted to do them. Those things were not possible in an institution. The vision of being home helped provide a whole person context well beyond the immediate needs of what they were able to do physically. Home was described in various ways including the central hub where family and friends congregated:

"I miss the social aspect that I had before" (P2, m, 96, T1)

None of the participants was certain they would get home. Most participants had expected to go home straight from the acute or sub-acute hospital so the transition to another service, TCP, was unexpected:

"They came all of a sudden…pack up straight away… all of a rush" (P1, f, 96, T1)

"When I was at Repat (rehabilitation hospital) I was to go home last Monday, but they came to see me the day before and they spoke to me about not being ready to go and about coming here for three weeks" (P7, m, 72, T1)

Many participants reported feeling overwhelmed at the unexpectedness of the transfer from acute and suddenness of the move to TCP. One of the unsettling surprises to clients was the speed of decisions to move from the acute hospital to TCP:

"Everything came at the same time" (P2, m, 96, T1)

There were challenges perceived with the new physical environment at TCP where each client had a single room and a bed without cot-sides, unlike most of the acute hospitals. This increased the feeling of uncertainty and fear:

"*I felt lonely at first... I was frightened to turn... it's totally different, it hits you when you come out of hospital*" *(P1, f, 96, T2)*

The timing for decision to transfer to TCP was simultaneous to identifying goals for the program. Participants described goal-making decisions being out of their control:

"Not being prepared" and *"It was a bit of a surprise actually" (P11, f, 79, T1)*

Many participants had been through a sequence of admissions in different hospitals, which added to the uncertainty of getting home from TCP:

"I never came (went) home from St Andrew's hospital and I had to come here because I was in too much pain" (P13, f, 80, T1)

The unexpectedness of the illness or health event that had led to hospital admission, along with being unable to go home directly from hospital, compounded the unpredictability regarding likelihood of going home from TCP:

“I really don’t know how I’ll go” (P12, f, 95, T1)

Some of the uncertainty related to participants feeling unsettled, unsure and unaware of what had been expected in the new service:

“When I came here, I didn’t understand it much of what will happen to me” (P13, f, 80, T2)

Aiming for home was the major reason to engage in goals, and the thought of not going home was far more distressing:

“I'd be doubly devastated, putting it mildly” (P6, f, 90, T1)

“(it would) break my heart” (P8, f, 82, T1)

The degree of illness and length of stay in acute hospital varied between participants, but there was a common perception of helplessness with uncertainty of how quickly they might improve:

“I couldn't do a damn thing for myself” (P6, f, 90, T1)

When the participants were asked how they would know they were ready to go home, there was deferral to the staff team:

“Getting enough, you know, ‘Okays’ from the medical people (P11, f, 79, T1)

In contrast, other participants considered they were capable of doing more than staff did:

“It puts them off that I’m 97. They think I’m too old and I’m not going to do anything” (P3, f, 97, T1)

“Well, I need to get home, and they don’t think I can look after my house but I think I can. It’s just, I’m full of aches and pains” (P13, f, 80, T1)

The fear of becoming an encumbrance to family related to the uncertainty of how much improvement was possible:

“That's what I'm looking for, not to be a burden on people” (P9, m, 83, T1)

For other participants, the uncertainty of going home from TCP related to how limited their physical function had been on arrival in TCP:

“I couldn't do a damn thing… I was just lying in bed. I couldn't even get to the toilet, I had to use a bottle and a pan, and all that sort of caper” (P9, m, 83, T1)

The significance of not regaining function and potential for continued dependence was expressed as a realization that the discharge destination might not be home, but could become a residential care facility. The awareness of their reduced physical function, particularly walking and transfers, created uncertainty in the moment and for the future. The fear of not being able to move or to trust their limbs to hold them up was a major concern:

“I can’t walk without the walker. I can’t stand properly.” (P1, f, 96, T1)

“As I walk, the knee just collapses” (P9, m, 83, T1)

Many participants experienced the ongoing fear of falling:

“I’m a bit afraid of falling again, which is a bit understandable” (P5, m, 68, T1)

“I went down like a sack of potatoes” (P10, m, 82, T1)

In addition to the fear of falling, participants also discussed the fear of not being able to manage the personal activities of daily living such as showering, dressing and toileting themselves at present, and also whether this would continue when they went home.

"I've gotta make sure that somebody's round the place if I'm having a shower" (P11, f, 79, T1)

"They get me up to walk to the toilet, no bed pans" (P6, f, 90, T1)

For other participants, the steps for the goal of going home were much clearer. They were able to identify that their ability to go home was dependent on improvements in their functional capabilities. These participants were keen to state their goals of improved mobility and physical function with staff, so that everyone was aware of what they wanted:

"They know I want to get on my feet and go back home to my house" (P6, f, 90, T1)

A further cause of uncertainty was seeing other clients less able than themselves:

"They can't cope, they can't talk, they can't feed themselves, they can't dress or anything else. And table times, some can talk, others just sit there and get fed. (P9, m, 83, T1)

These observations compounded the desire to be able to go home themselves:

"I want to try, as quick(ly) as I can, to get home into my own place (P1, f, 97, T1)

However, this participant explained how the admission to TCP had caused uncertainty with the change in service. The TCP was a new venue and introduced unfamiliar staff and unknown routines, thereby increasing the uncertainty. She had been in a shared ward in the hospital and was lonely and scared the first night in her own room at TCP, causing distress:

"Well I only came yesterday. I've got to get used to it, this is the problem. I was so used to having company. And it's… last night it was very hard... Oh gosh, I couldn't go to sleep. Oh, it was dreadful last night." (P1, f, 96, T1)

Within a week of admission to TCP, one participant knew she was going to a new home:

"The chances are I won't be doing things I've been doing before, like getting out in the garden, I won't be doing anything like that. I'll be going into a nursing home" (P12, f, 95, T1)

TCP has a functional approach of low-level therapy and personal care to assist with improving physical functioning. Some participants were aware of additional supports that were likely to be required to be able to go home. 'Support' emerged as a theme that influenced the two main goals of 'home' and 'normal' and is explored later in the chapter.

Going home

At discharge, T2, the participants split into two distinct groups – those who had achieved their goal of going home, and those whose goals were not attained, had to be modified or replaced, and were instead going into residential care, a new home.

The group who were going home experienced a sense of achievement for the physical and psychological improvements that meant they were going home. For them, going home epitomized participating in and attaining goals:

"Every day got better.. it did, really, yes… amazing… I'm walking a lot further and all that" (P1, f, 96, T2)

“I started by endeavoring to take a step longer, stretching more, manage on the steps and then having reached that, I was endeavoring to walk faster, then eventually I was able to walk at quite a pace” (P2, m, 92, T2)

“Getting in and out of bed and walking” (P8, f, 82, T2)

These participants was pleased to be leaving TCP and going home. The interviews at T2 provided an opportunity to reflect on the emotional as well as physical journey undertaken in TCP.

“I’m glad to get home. It’s been a long haul.” (P6, f, 90, T2)

For those going to their own home, uncertainty tempered the sense of achievement regarding how they would manage once home.

“I guess I won’t really find that out until I get home and perhaps start to do something that I used to be able to do” (P9, m, 83, T2)

Going home meant an end to illness and the hospital system and starting finally to feel a bit better:

“I’ve never been so sick in all my life… I was a miracle to get over it” (P1, f, 96, T3)

It reinforced that the episode of illness and dependency was over:

“The hospital situation was Flinders (acute hospital) for 2 months, and then 3 months at Repat (sub-acute hospital), and then…to TCP” (P4, m, 76, T3)

Home also represented normality and a return to previous activities:

“I wanted to come home first of all. I wanted to live here, and I wanted to come upstairs” (P2, m, 96, T3)

Once home, participants were pleased to have achieved their goal of going home. Being home meant that participants were able to do the things they wanted, in a time that suited them, without the constraints of an institution:

“Yeah, extremely happy... I get up in the morning and I look out the window and see all the trees and plants, even though it’s all weeds. And it looks great, you know?” (P8, f, 82, T3)

One participant who lived in a quiet cul-de-sac was grateful for the peace and quiet after being in the hospital and TCP and was enjoying the ability to sit outside on her veranda in the sun and chat with neighbours as they came and went. The bonus of fresh air to good company was a huge positive:

“When it is decent weather, I sit on my front veranda” (P6, f, 90, T3)

Unlike the group who returned back home, the group who did not attain their goal were settling into a new home.

New home

The discharge from TCP into a new home meant this participant sub-group had not achieved their goals of going home. For this group of participants, their goals had to be modified or replaced, and the participants had to start again with another transition, new goals, and revised expectations of themselves, family and new staff:

"You know, they (son and daughter) said 'you've got to be realistic'. I said 'Yes. I worked so long to get this house, I paid it off, it's mine. Why would I want to do anything else but to go back there?" (P5, m, 68, T2)

One participant was aware she was not going to her own home within a week of her admission to TCP and discussed this at the initial interview. Her main goal on admission was to:

"*get better"* and *"to cope… with all this transition." (P12, f, 95, T1)*

This participant clarified

"Well, I won't be going home, I'll be going into a nursing home… That's for sure. It's been decided. I really don't know how I'll go" (P12, f, 95, T1)

The thought of not going home was difficult for her:

"It's a little bit hard to swallow" (P12, f, 95, T1)

Others reiterated the disappointment, anger and frustration of not going home in this sub-group of participants:

"No. it was hard, very hard. Because I've worked all my life, I've brought a home…and I thought I'd just go to my home. But, it's not working out that way... I feel a bit disappointed that I had to make this decision, where I didn't want to make that decision."(P5, m, 68, T2)

"I was very angry at first because I couldn't go home"…"I've had to give up a lot of things that I thought were a part of [me] you know" (P7, m, 72, T2)

In contrast, another participant in this group was looking forward to moving into the residential facility:

"I've got friends there which I have known for ages and they're already there, so I quite look forward to going" (P3, f, 97, T2)

After talking about the move to the new facility, one participant brightened up when he discussed the animals in the new home:

"*They've got a dog there which goes around up and down the hallways. It's a Labrador. Beautiful! And you can pat it and it just sits here. And they've got birds in the aviaries. I love birds and I love dogs..." (P5, m, 68, T2)*

This reflection seemed to provide a degree of tempering for the fact he was unable to return to his own home. The anticipation of a new home was met with the uncertainty for these participants and how they would settle in their new home. This group had actively engaged with goals throughout their TCP stay but had not attained their primary goal of being able to return to their own home. All participants going to residential care were aware of the new goals for the new venue

"I am clearer in my mind of what these places can do for me" (P7, m, 72, T2)

These clients talked of taking time to reflect and come to terms with why they were going to a new home, what it meant to them and their families. Letting go and coming to terms with this was an ongoing process:

“My idea was to get well enough to go home…but this has changed now” (P5, m, 68, T2)

“Being aware of the things I can do and can’t do” (P7, m, 72, T2)

“Well, I suppose that’s what you expect. It’s been quite an experience being in different places.” (P3, f, 97, T2)

Participants in a new home had mixed reactions to new goals in the new home:

“I’m just sort of muddling along now… so, I wake up, they give me breakfast and I just potter around, do a few things here. Not much… Oh yeah, they shower me and dress me” (P5, m, 68, T3)

For two participants, the new home had new systems and learning to deal with them was additionally unfamiliar:

“I don’t like being told what to do but there are certain things here under their rules and regulations that I have to deal with” (P7, m, 72, T3)

One of the participants was resigned to living with the rules:

“I don’t have a house now, and I live here so that’s the end of what I used to want to do, you know.” (P5, m, 68, T3)

The original goal had been to go home and this had not been achieved. When reflecting back on their other goals at TCP admission, this group of participants identified that their goals had required modification or changing:

“They were right at the time… But things have changed slightly” (P5, m, 68, T3)

“Too optimistic, I think, too optimistic” (P3, f, 97, T3)

“I have accepted the fact that my goals, my legs, are probably still the same. I had to accept the fact that they were getting worse. And I had to go with that.” (P7, m, 72, T3)

These goals relate more to returning to ‘normal’, which forms the second theme to emerge from the data.

Theme 2 Normal

The second main theme to emerge from the data was the participants’ wishes to get back to normal. ‘Normal’ incorporated returning home but was also related to the functional level and activities undertaken prior to the acute health event, hospital admission and entry to TCP. The ‘normal’ for each participant differed and was both situational and contextual. Participants who had been active in the community had goals that related to driving again; pet owners had goals that related to caring for their cats and dogs; grandparents had goals related to their interaction with grandchildren. Some of the goals were formal and some were informal. At T1, ‘return to normal’ was identified as a broad goal that provided motivation to go home:

“To be able to achieve what I want to achieve and that's go home and live a normal life again” (P4, m, 76, T1)

Fear of not being able to return to normal and goals that might not be achieved was expressed in different ways:

"My big concern about getting home is whether I can kneel down to the ground to fiddle if I need to" (P9, m, 83, T2)

"I think just normality; I want to just be a normal 77 year old. I don't want to walk around with a hooped spine, a walking stick or having to join a bowls club. Those sorts of things don't appeal to me at all" (P4, m, 76, T2)

Getting back to normal was a way of measuring progress and identifying recovery from the acute illness that had brought the participant to TCP:

"I used to be on my own. I used to do my own shopping, some cooking, and driving my car" (P5, m, 68, T1)

"Well my main goal is to get back on my own two feet" (P6, f, 90, T1)

When the concept of 'normal' was explored, many participants explained in very general terms:

"I'll be free of pain; I'll be alright and back to normal" (P4, m, 76, T2)

"(I) looked at what I used to do and what I wanted to regain" (P5, m, 68, T1)

"Well, just to make sure that I can go and do what I need to, be done" (P11, f, 79, T1)

Some participants were able to identify a relationship between the activities undertaken in TCP with the broader goal of returning to normal:

"maintain.. or regain the sufficient strength in my legs and.. go on with my own life.. I feel that if I can do this, I'll be able to go back to the normal life I was leading" (P2, m, 96, T1)

"But I look at all my physio' that they give to me as a challenge. To make me stronger, I have difficulty with my balance, and I'm frightened of falling" (P10, m, 82, T1)

For some participants the 'return to normal' related to confidence in ability:

"to make myself confident that I can look after myself" (P5, m, 68, T1)

Pursuing normal became a measure of goal progress or goal attainment:

"..when I feel that I don't need that (indicating walker) *to walk anywhere" (P2, m, 96, T1)*

In many cases, 'normal' was associated with the participant's self-belief:

"I think if you got an aim, you can work for it." (P8, f, 82, T1)

"Well it just means that if I want to get there I've got to work at it." (P5, m, 68, T1)

This intrinsic motivation, the motivation to achieve their goals generated by the clients themselves, was expressed in a number of ways:

"I've learned to not set my goals too high and also not too low, so that I get some pleasure out of achieving something." (P8, f, 82, T1)

"To do these things without any outside influence or outside help... I just like the joy of achieving something and then looking back and saying 'wow, did I really do that?' you know?" (P4, m, 76, T1)

Some participants were aware of the role of motivation in their lives generally:

"Don't blame other people for your situation, never look down on people who are lesser than you because that will take you down a level, always stay around motivated people and

keep yourself motivated" (P6, f, 90, T2)

For many participants, the goal of 'back to normal' meant that exercise activities in the TCP were a means to an end, such as improving physical function:

"I always want to do that little bit better and go that one better... I'll have a crack and I'll keep on trying" (P7, m, 72, T1)

However, the single room set-up meant that non-mobile participants were dependent on the staff to move them around the facility. If this did not happen on a regular basis, then there was potential for increased dependence and social isolation, which potentially hampered a return to normal:

"Because when I first came here, I didn't go anywhere, I had my lunch in here, my dinner in here, my breakfast in here." (P5, m, 68, T2)

For others, making progress with therapy or walking provided the motivation to continue pursuing goals:

"It's no good me sitting here saying, "oh it's going to be painful, I don't think I can do it". Load of rubbish! If I want to get back on my feet... no pain, no gain! ...It means continuing, ongoing, despite the struggle, to improve myself and get back on two feet and independent..." (P6, f, 90, T1)

Participants were able to identify and celebrate their goal achievements during their TCP stay:

"I can take my medication myself" (P10, m, 82, T1)

"People help you to get more strength and able to go home… you sort of get your legs moving if you can. I'm alright, I've got on alright" (P1, f, 96, T2)

Self-belief was inherent in the participants' self-determination:

"...so I think damn it, I'm going to do that!" (P3, f, 97, T1)

"I have to be able to demonstrate that I can do enough things so that I can go home and look after myself" (P5, m, 68, T1)

"I don't want to say I just can't do this goal to weaken the belief in yourself… I don't want to lose that belief" (P6, f, 90, T1)

Looking after themselves again was the driving force and motivation for many participants:

"*Every time I do something more I feel like I'm getting there" (P6, f, 90, T1)*

"They don't think I can look after my house but I think I can" (P13, f, 80, T1)

For others, self-belief was not always so overt. Sometimes, the courage of the belief was stronger than the conviction of attaining the goal:

"I want to believe I can do these things" (P7, m, 72, T1)

"If I can get motivated and keep motivated then I should be out of here in a week" (P8, f, 82, T1)

Participation in the functional retraining programs offered by occupational therapy and physiotherapy were enjoyable and participation in these had contributed to their improvement. Some clients experienced real joy with being able to work out and regain physical ability:

"..and then you sit there on, like, on a bike, that's amazing, (laughter) treadling and pedaling (laughter)… everyday got better!" (P1, f, 96, T2)

Participating in the day-to-day activities provided a means to identify progress towards the goals of normality and independence:

"I know this is the most ridiculous goal to set, but you know I can now wipe by own bum? Never in my whole life did I think that would be some goal!" (P6, f, 90, T1)

"Now I've got that thing (indicates monkey bar) *I can actually heave myself up in a bed and swing my legs over" (P8, f, 82, T1)*

Staff support was appreciated although the challenge from the opposite gender providing personal care proved to be a bit challenging:

"Well I'm not used to stripping off in front of people, particularly young girls and all" (P9, m, 83, T2)

"it took me quite a while to accept nursing staff, male as well as females, wiping my bottom and showering me and so forth" (P9, m, 83, T2)

"I found there was a lot of men there that worked, and I had to get used to that… there wasn't a lot of ladies, like, showering you or whatever. I had to get used to that" (P1, f, 96, T3)

This created motivation to be able to manage the activity independently. Participants' limitations in function, such as a restriction in mobility with reliance on a walking frame, was a common motivator to engage in goals for functional gain. For these participants, the motivation to participate in the therapy sessions was to improve strength and regain lost function:

"*Well I'm trying my hardest… Yeah, I've had top marks so far... But I look at all my physio that they give to me as a challenge, to make me stronger... My aim at the moment is physio' so it'll make me strong*" *(P10, m, 82, T1)*

"*Every time I go another couple of meters, I'm improving" (P6, f, 90, T1)*

Back to Normal

At T2, no participants had achieved all their 'return to normal' goals but many had achieved some of them. Many participants were still working towards attaining their 'return to normal' goals, and some had not attained any of them. Those goals aligned with 'return to normal' that had been attained most often aligned with functional activities of daily living that indicated readiness for discharge home:

"*I've been showering myself, well, the best part of a week now" (P2, m, 96, T2)*

"*In the morning I shower and get dressed and go and get my breakfast and I bring it back here" (P2, m, 96, T2)*

"I had to make breakfast, I've done that. So I was able to do that, some toast, boil a kettle, make a coffee" (P5, m, 68, T1)

Some clients were surprised at their goal achievement because they had not anticipated making so much progress:

“I found that I’m doing better than what I ever expected to do... I can walk… not very well, but I can walk!” (P8, f, 82, T2)

“I feel that, from some of the progress that I feel that I've done, considering everything, I think I've achieved something (P2, m, 96, T2)

The enormity of the progress and achievement was significant. Participants reflected on how sick they had been and how much effort it had taken to recover from the illness and fatigue and recover to make progress:

“I don’t think I’d like to go through it again... It really is hard work” (P8, f, 82, T2)

Some participants had held doubts about improving, but their self-determination was evident:

“..*otherwise you have nothing to fight for, you know um, I am a fighter (*laughter) and each time I’ve been to hospital they’ve admired my grit and to keep on fighting… but I don’t think for one second I’ve lost the will to fight*” (P8, f, 82, T2)

Within the group of participants who had gone home, there were some ‘return to normal’ goals that had not been achieved but participants were continuing to make progress towards achievement, for example not yet being independent with showering and dressing, or managing stairs:

“I think I’m going to have help for a start. Somebody will come in and just kind of oversee me” (P6, f, 90, T2)

“*But at least I can get up and get down (a step)* ***i****n the safe way whether I need to or not” (P9, m, 83, T2)*

This was considered a period of adjustment for some of the participants:

“I mean, it’s not earth shattering so, what? It’s a relearning, you know? And that’s that.” (P9, m, 83, T3)

In some cases, participants perceived potential progression had been hampered by the organisational structure or service delivery, such as not being able to practise activities:

“At the gym I've noticed that they've got an outside room. In that outside room you get a step, but I've never seen anybody trying them” (P4, m, 76, T2)

Some participants experienced frustration with being constrained to an individual room being unable to participate in social or recreational activities unless a staff member came to collect them. The isolation in an individual room created boredom, something that was not welcomed, but somehow seen as inevitable to being in the program:

“I know the people I bump into also, they’re bored to death” (P7, m, 72, T1)

“You can see them nodding off, or watching everybody else - they are just totally bored” (P8, f, 82, T2)

A further group of ‘return to normal’ goals that were unable to be met within the participants’ stay in TCP was due to the constraints of the service, which did not have the resources to support goal pursuit for activities such as driving, so these ‘return to normal’ goals were identified for ongoing attention after discharge from TCP:

"I'll be alright and back to normal, and once that's achieved, then I can return to driving" (P4, m, 76, T2)

Some challenges for returning to normal may have been how the therapy was provided. When provided with an opportunity at discharge for reflection on their stay, participants reported that the intensity and frequency of therapy was less than expected. For example, therapy sessions were described as being run in a very busy room but with little therapy seeming to occur and not to the intensity that the client expected. This suggests a mis-match between expectations and actual provision of therapy and a lack of support from staff:

"I'm not satisfied with having to be taken (in a wheelchair) to a meal when I'm quite capable of walking" (P3, f, 97, T2)

"...and that got a bit sloppy in the end.. You know, I'd go up there and I'd sit in my wheel chair… I didn't get half the amount of treatment that I needed to get." (P8, f, 82, T2)

"I don't think that they (exercises) were strong enough, or progressive enough. They certainly, I went up to their gym, two or three times a week and more towards the end. But they weren't pressing me, they didn't push me, or anybody else" (P9, m, 83, T3)

The final group of 'return to normal' goals that were not met within the TCP admission constituted activities where a service or assistance could be offered in the short or long term, such as personal care provision for participants going home who were unable to manage these activities of daily living in an independent manner:

"I'm having someone come into help me shower, and I already have ACH (service provider) doing housework and bed change" (P6, f, 90, T2)

Continuing to plan 'return to normal' goals after discharge indicated a fundamental shift in thinking, by not accepting the status quo and continuing to pursue higher goals:

"I aim to continue to go upstairs" (P2, m, 96, T2 of their two-storey home)

"Then I can return to driving and have those things in life that I treasure" (P4, m, 76, T2)

Whilst these clients were pleased with their progress to leave the program and go home they did not accept their current functional status as finite and wanted to continue engaging with their goals beyond their TCP stay once they were home:

"..working towards as much as I can physically" (P9, m, 83, T2)

"..to be able to walk freely like I was before having to have a walker. Just get up and walk across the room really." (P6, f, 90, T2)

"I'll have some physio at home, and I'll explain to that person that with getting upstairs,.. I aim to continue to go upstairs using the stairs. I mean, I've got the chair lift but I'm not ready to use that yet" (P2, m, 96, T2)

Those participants going home with some degree of 'return to normal' were thankful for the recovery, for improved health status compared to their admission to TCP and for feeling settled again instead of uncertain, even if all the goals were not attainable:

"I'm not going to be able to do everything that I was determined to do, can see myself doing… it's too much" (P8, f, 82, T2)

Return to normal was not articulated as a goal within TCP and the lack of explicit conversations about goals was a barrier to progress. Whilst the goals had been identified and set in the acute hospital prior to arriving in TCP, participants expressed frustration that no one had talked about them explicitly since:

"No one has actually spoken to me about the goals… No one has discussed or talked about the goals at all… don't know if she has actually seen and read what my goals were… we haven't talked about goals, we just looked at my wellbeing… some have been ticked off which means the staff here have said its okay… no staff member has spoken to me about them" (P9, m, 83, T2)

This has major implications for the approach to goals in the clinical setting of this service. Some of the daily activities were beyond the participants' capabilities, and this introduces a new sub-theme, 'new normal'.

New Normal

This sub-theme encompasses two participant groups: the first who went home but were having to adjust to new circumstances in their homes, such as restrictions on usual activities, new services, or having different support staff come and visit them at home; the second who had not gone home at all, but had discharged to a new residential care facility (RCF).

In the first group, the usual activities of daily living required assistance, and adjusting to the new status of dependence was frustrating. One participant had been walking prior to TCP admission but was in a wheelchair for most of the day on discharge. She accepted being in a wheelchair as the most practical method for being at home, however manoeuvring the chair independently around the kitchen and lounge area was beyond her:

"I haven't got, learned how to park it next to the sink or next to the cupboard. I can't get there. I get upset and… you know I can't... even to wipe up, I can't come in like that… Little things, by gee, they annoy you." (P8, f, 82, T3)

The lack of physical ability and associated functional restrictions to do what had been 'normal' or 'usual' was being grieved and recalibrated. Some of this grief was for major ideals for living:

"I know I can't walk and can't do the normal things that I use to do, like hop in the car and go for a walk along the beach or do something like that... this mobility problem, not being able to do what I want to do, it makes it very hard to sustain that type of lifestyle that I'm used to" (P4, m, 76, T3)

The lack of energy and loss of function were two of the many things being grieved. These affected what was possible on a daily basis, and for some, it meant grieving for things that had brought much pleasure before:

"One thing I really miss is… one (daughter) has two dogs and I loved.. taking them down to

the national park…and taking them for walks. And I got a great deal of pleasure doing that" (P4, m, 76, T3)

In addition, small daily events that did not go according to plan also caused grief and frustration:

"some of the normal things that I used to be able to do, like making a cup of coffee for myself in a machine… and I had to stop and think about how to do it. In fact, the first coffee I made, it was a cold coffee because I didn't understand" (P9, m, 83, T3)

Likewise, the regrets with activities that had not been completed in the past meant a review of goals and recreation of what would be the new normal:

"*you feel that so many things that you ought to have done and now there isn't enough time to concentrate because of the other things" (P2, m, 96, T3)*

The group of participants who were going to a new home were grieving for what was familiar and their 'normal'. Whilst the participants who had moved into a RCF were glad to be finished with the hospital and health systems, they were now having to become familiar with their new surroundings, different staff and changed routines, some of which were quite challenging:

"You know, there was an attitude sometimes, "oh what a nuisance" you know? I just rang the bell to get some help and might be wanting to go to the toilet… but it is annoying. We are under their thumb very often." (P3, f, 97, T3)

For this group of participants, a new home provided the care, security and safety but without any familiarity. The understanding of what was normal had changed and they grieved their homes:

"I don't have a home, I live here now… I don't have a house now, and I live here so that's the end of what I used to want to do, you know, yeah." (P5, m, 68, T3)

I feel a bit disappointed that I had to make this decision, where I didn't want to make that decision. (P5, m, 68, T3)

Part of the grieving was the inability to participate in the usual activities in the community:

"'I would love', I said to one of my granddaughters the other day, I said, 'a day in, an afternoon in Coles (supermarket) or someplace like that, amongst the fruit and everything like that and just wandering around, thinking I'll try this and this.' I'd love that. Just an ordinary yearning to be an ordinary shopper. But I'm not." (P3, f, 97, T3)

All participants who moved into RCFs had mobility problems that meant they were unable to stand or transfer out of bed or chair independently. Each had sustained falls prior to and during TCP admission. They shared their frustration with their inability to get up and move about when and how they wanted. Participant 3 had leg weakness and was limited to moving around the new facility in a wheelchair. She was able to manoeuvre around her own room in the wheelchair but required someone to push her to meals and activities throughout the day, which caused consternation:

"I still get concerned about the distance between here and the dining room, which is a lot,

because I'm using my arms and my feet and my walking is virtually is non-existent" (P3, f, 97, T3)

Although he would have preferred to go home, Participant 5 acquiesced with his son and daughter's recommendation to move to the RCF where care and assistance was immediate:

"So, now I just have a button and I press it and within a reasonable time they come and look at me, look after me. Yeah" (P5, m, 68, T3)

He had a walking frame on the far side of the room to his chair and commented:

"*So, I get up and I think 'Ah', because I have a walker over there and I'm* supposed *to use that every time I move, but, you know…" (P5, m, 68, T3)*

The third participant who had moved to RCF was more pragmatic about his lack of mobility:

"*from the waist up the way I'm still carrying on but, from the waist down, everything's gone… so that's a problem, not being able to be mobile." (P7, m, 72, T3)*

"I have accepted the fact that my goals, my legs are probably still the same. I had to accept the fact that they were getting worse. And I had to go with that." (P7, m, 72, T3)

The lack of mobility caused frustration with not being to move between chairs or rooms, but there was also an underlying fear of falling again:

"Well, walking is a problem and the problem (I'm) always facing is the falling." (P3, f, 97, T3)

"I've had several falls (in the RCF), yeah. Look here, and here, and here (indicating bruising and bandaging on arms and legs)" (P5, m, 68, T3)

"The thing that I have got to do now after getting the blood clot on the brain, is concentrate when I walk, on balance"(P7, m, 72, T3)

Creating the new normal was also about establishing boundaries between the participant and new staff, regarding what was acceptable, what was preferred and how the participant would prefer to spend their time in the new facility:

"I have a goal, as far as myself not to get annoyed in particular... I usually join in most things because I think I can do the activities anyway, but I can do them back to front and I think I just love sometimes to read." (P3, f, 97, T3)

"They expect me to be out in the garden and walking around their garden and going to their dining room each night. I'm not that type of person you know?" (P7, m, 72, T3)

The ambiguity for them was to maintain their own identity at the same time as settle, relax and feel at home:

"I long to know that I have time to read without somebody coming to call me" (P3, f, 97, T3)

Future plans were curtailed due to loss of functional mobility:

"I would like to go on another trip but I'm just not physically capable now" (P5, m, 68, T3)

Two of the participants had had their driving licenses revoked since discharge from TCP. For one of them, this coincided with admission to the RCF and he was grieving for both losses – home and car:

"I sold my car to my son because I don't drive and yeah so, I don't have a home, I live here

now" (P5, m, 68, T3)

The second participant to lose his license had been actively involved with a car club for most of his adult life and his grief was still acute:

"I'm still in the club, but only as a fringe-dweller. I'll do all the registrations for the cars but that's the thing, that's an impossibility now… I'm going to have to virtually close the chapter of my life as far as the club goes, as far as what was my responsibilities." (P4, m, 76, T3)

Driving in the community was no longer possible for these two participants for whom cars and driving had supported their identity and standing in the community. The emotional effects of grief are explored in the next theme, 'fatigue'.

Theme 3 Fatigue

Fatigue was a common theme across all time points and influenced the pursuit of goals at all three time points. On admission, fatigue affected physical and mental function:

"I'm absolutely spent. No other word. It's been such an ordeal... took me right down to nowhere… the depletion of energy… I could do nothing. I was in a terrible state" (P6, f, 90, T1)

The physical effects of fatigue took their toll on the participants who were exhausted:

"*I am tired and useless - no not useless, very listless in the mornings" (P8, f, 82, T1)*

"..washed out and feel like, you know, I didn't want to get out of bed" (P10, m, 82, T1)

Some participants also had irreversible conditions where the effect of the illness itself created fatigue:

"Because I've got the myeloma, you know the cancer; well that's why I'm so tired" (P13, f, 80, T1)

All the participants were aiming for home and to get back to normal, but their ability to practice the functional activities was affected by the effort and energy required to join in or recover from the session. Participants' engagement in the therapy activities was hampered by the fatigue during and after the exercise:

"Today I did physio and a bit of walking and exercising and it knocked me around… I couldn't do it properly" (P8, f, 82, T1)

"*I find that at the end of it all I'm totally energy expended" (P6, f, 90, T1)*

"Getting better would include something to do with higher energy, more energy" (P12, f, 95, T1)

Fatigue was also associated with nausea and the combination of nausea and vomiting was exhausting:

"I was vomiting from all the drugs. I was in a terrible state" (P6, f, 90, T1)

The energy input from food was discussed in no detail, other than the comments regarding little interest in food:

“I have a poor appetite” (P3, f, 97, T1)

“I'm diabetic and got wheat allergies, so I'm pretty damn selective with what I eat” (P6, f, 90, T1)

At admission, pain created a physical barrier to engaging in therapy and contributed to fatigue. Participants declined to attend therapy due to pain, or attended but did few exercises, or participated with exhaustive consequences:

“*pain in the knee, oh it’s all worn out in between the bones” (P1, f, 97, T1)*

“I’ve got sore knees, sore here we are (pointing to legs), right and left knees and right and left buttocks yeah, ‘cos I landed on my buttocks straight down. Both sides are very sore” (P5, m, 68, T1)

“It's incredibly painful; it's totally energy draining” (P6, f, 90, T1)

The impact of pain on goal pursuit was affected secondarily because of the effect of pain on motivation and energy levels:

“I was pretty sore, I came back here, (as) soon as I sat down I fell asleep. Ah it’s the result of the effort - I was, yeah, tired, yeah” (P5, m, 68, T1)

Restorative sleep was not common for the participants at admission, and this contributed to further fatigue:

“Even when I do go to sleep, this morning I woke up halfway through the night” (P9, m, 83, T1)

“I did sleep but woke up a few times” (P13, f, 80, T2)

Some participants were unable to participate in therapy because of sleeping more than usual:

“Yeah I’m asleep all the time and I’m not a sleeper usually” (P13, f, 80, T1)

Further, fear of pain or falling was mentally exhausting:

“I know it's going to be a lot of hard work. I know it's going to be painful. The more I do the more painful it becomes” (P6, f, 90, T1)

“I’m a bit afraid of falling again” (P5, m, 68, T1)

The effects of mental fatigue at admission were a combination of emotional and psychological exhaustion. The uncertainty of transfers between hospitals with the worry of whether they would get home again was emotionally fatiguing for participants. Some participants were concerned with fatigue affecting their ability to think or express themselves clearly which affected their engagement:

“I was having real problems trying to speak rationally or speak without losing what I was talking about” (P4, m, 76, T2)

“Now you’re asking for memory (laughs) that’s the thing that’s not good” (P5, m, 68, T1)

“My brain’s not working today” (P11, f, 79, T1)

Participants described their uncertainty with the move into the program and the effects of worry being exhausting:

“to cope with all this transition. I really don’t know how I’ll go” (P12, f, 95, T1)

The uncertainty of discharge destination or likelihood of going home or returning to normal created a cycle of uncertainty, anxiety and emotional fatigue:

"I just felt totally drained and I just can't go anymore… (I need a) recuperation period to get it all back together again" (P6, f, 90, T1)

Being surrounded by strangers in the health environment was exhausting for some participants, especially when the others had unfamiliar mental or physical disability:

"I was ready to go home mentally because, it was so dreadful to me to see grown men, some who could barely talk, others had to be fed at my age and strapping younger men, who were in the same boat" (P9, m, 83, T1)

Fear was wearying and sometimes carried from the past:

"more my mental health towards the shower, and people coming into the shower as a small boy and not being safe in the shower… so, I never felt happy in the shower" (P7, m, 72, T1)

By the time of discharge, some participants may have been less physically fatigued, particularly the participants going home. Their improved physical functional state had permitted them to participate actively in more therapy activities and some participants were celebrating the improvement:

"all the people trying to walk and do exercise, and it's amazing it is, how it helps" (P1, f, 97, T2)

For some, the fatigue and pain had impacted their ability to engage and participate throughout their TCP stay:

"The pain that I have in my feet and my knees to start with, this restricted my walking and doing the exercises" (P2, m, 96, T2)

For others, the fatigue continued to be a barrier to goal progress:

"I'm not getting better, I'm also getting weaker" (P8, f, 82, T2)

"I haven't got much energy, I'm not strong." (P13, f, 80, T2)

Fatigue was not solely the domain of participants of this study, but also noted in other TCP clients:

"Well, one of them will fall asleep while eating his dinner" (P4, m, 76, T2)

The mental fatigue at discharge was associated with uncertainty about managing at home or in the new facility:

"..no walking, um, adjusting to everything, you know?" (P8, f, 82, T2)

Some of the participants had achieved their goal of going home and for some, this was energising, but for the others, it remained overwhelming:

"Hopefully I can build it up, because now I have no energy" (P13, f, 80, T2)

Fatigue associated with feeling demoralised was made clear:

"Then he (staff member) comes along and… made me come through that door, and I could hardly walk. I was in pain, it was hurting and he made me get to the door and then turn around, and I only made it back to that chair, because he said, "no, get back to your chair".

That's flattened me… I hoped to hell that I could do it and that he'd go away and leave me alone. And I just ended up in a ball of tears...things like that can take you down" (P8, f, 82, T2)

By the three-month follow up, physical fatigue from irreversible changes had manifested from the acute and sub-acute admission:

"I was very tired with getting things done and I don't know where I was but next minute I had hit the wall and down I went" (P7, m, 72, T3)

Physical fatigue was easier to manage in the participants' own home:

"I just felt completely lazy. I was quite happy to sit there and read or if I, when I was home, and not do anything" (P2, m, 96, T3)

Psychologically the fatigue related to another transition, especially for those participants going to a new home. The repeated uncertainty with another transition caused further emotional and psychological fatigue. The effects of fatigue in the new facility were to become passive or disengaged:

"*I'm just sort of muddling along now… It's just like that you know? I live here and this is my whole world here" (P5, m, 68, T3)*

Those participants who had returned home were facing uncertainty or lack of confidence to take the next step:

"There are times when I just don't want to think about it and analyze it because that's all, that's, I don't need to do that all the time" (P7, m, 72, T3)

The emotional toll of anxiety was fatiguing:

"Whether it's I'm afraid I'm going to fall or what, I'm so careful you know, all the time (P1, f, 96, T3)

"I'm still plucking up courage to use the gopher to go up to the shops to do whatever I want to do out…I want to pluck up enough courage to get the 2 sticks… and see if I can walk" (P9, m, 83, T3)

The desire to reconnect with the broader community also required additional energy:

"Probably drum up a bit more energy to get out and about a bit" (P6, f, 90, T3)

Participant confidence was bolstered by seeking reassurance from staff, providing extrinsic motivation. This was part of the support system that participants identified and is explored as the next sub-theme.

Theme 4 Support

This theme emerged from participants sharing their experiences of how family, staff or each other supported them with their goals to get home and get back to normal. The support was unique for each participant depending on their situation and context but overall, support had a different emphasis at each stage.

T1 Care is the priority

At T1, participants had just arrived in the TCP and were unable to return home just yet. They had finished their journeys through the acute and sub-acute systems and these were still fresh in their minds on arrival in TCP. The potential of not returning to full health again, or relapsing with their medical illness was unsettling and caused uncertainty. Some participants continued to be reliant on the expertise of medical staff to solve problems:

“My breathing is so difficult, I insisted that I saw him (medical consultant), you see” (P2, m, 96, T1)

However, other participants understood that TCP was a care provider, that the acute medical care time had ended and it was time to be more proactive with their own goals:

“trying now to get so we’re no longer in hospital or no longer having to rely on people or specialists to get me over this hurdle” (P4, m, 76, T1)

“I talk to myself and I think, well, these people here, are here just to get me physically fit, you know?” (P9, m, 83, T1)

The practical care at this time in TCP provided daily support from staff with personal care and therapies to provide a focus on recovery. The frequency of care staff support meant that the participants felt supported:

“There’s always someone popping in to say, ‘Would you like a cup of tea or a cup of coffee or a couple of biscuits or something?’” (P3, f, 97, T1)

The restorative focus of care supported the participants to work towards goals related to their function and aimed to alleviate some of the fear of becoming a burden to family:

“I just don’t like the idea of being partially handicapped and having to rely on other people in the future” (P4, m, 76, T1)

“My main goal is to get us back home and be well again and get back into our routine.” (P10, m, 82, T1)

The therapy provision was supporting the participants to improve their physical status and become more independent with physical tasks which was seen to be very helpful:

“The person that I went and saw in TCP today at the gym said that I did very well today...It's making my body stronger” (P10, m, 82, T1)

Concurrent to the care support provided by the staff was the psychological support from family and friends. This reassured and motivated the participants with their aims for home and to return to normal:

“We give each other affirmation and the support where the other one needs it” (P10, m, 82, T1).

All participants except one had supportive family members such as spouses, children or grandchildren living with them, or close by, who provided lots of emotional support:

“I’m lucky with my family... I have granddaughters who are very good.” (P3, f, 97, T1)

“My family is marvelous... they support me 100% you know.”(P4, m, 76, T1)

“Family who are even the slightest bit interested in your well-being; good-oh!” (P9, m, 83, T1)

Social support was a frequently identified motivator by participants, and re-connecting with friends, family and acquaintances was integral to the goals for going home and getting back to normal. The social support worked both ways with participants expressing their support to fellow clients in the service at therapy session time or sat at the table with them for meals:

“At the meals that I’m here, I talk and I try to get people talking” (P3, f, 97, T1)

T2 Services to be arranged

At discharge, participants had either recovered enough to plan going home or plateaued in their functional level and were being discharged to a new residential care facility. The emphasis of support at this stage moved from hands-on care and therapy provision to practical arrangements for equipment or services:

“hospital bed… district nurse three times a week, I think it was, might have been everyday I’m not sure, ah… it was all left to my son” (P8, f, 82, T2)

Services such as cleaning, shopping or personal care may have been required on discharge, so for the group of participants going home, this meant the support provided was to advocate and arrange for services to commence in readiness for the participant’s discharge:

“I knew I had to have more help” (P1, f, 96, T2)

“They'll see what the house looks like and what I can do and then possibly offer to do some assistance as well” (P2, m, 96, T2)

Discharge planning required close liaison between the participant, their family and the staff member to identify what was already in place and what additional support was required. The family role at this stage changed from psychological to practical arrangements for discharge and what family could provide in the way of support at home on a daily or regular basis:

“My daughter said she will leave stuff on the bench out, so that I don’t have to keep bending and getting anything from anywhere” (P6, f, 90, T2)

“There’s one (daughter) at home with me and three within cooee” (P9, m, 83, T2)

“(My daughter) she’ll be around to help… She’s only around the corner from me” (P13, f, 80, T2).

Therefore, the priority at discharge was identifying what had been in place prior to admission, what additional was required for discharge and then arranging services to fill the gap. The effect of support at this stage was to provide hope and motivation:

“There is hope... It’s hard to keep it, you know, keep up with it” (P8, f, 82, T2)

“what I can do for myself, ridiculously independent to do what I can do” (P7, m, 72, T2)

The participants were satisfied and encouraged by the additional help as it was seen as a stepping stone to achieving their main goal; accepting the help meant they were able to go home.

For the participants going to a residential facility, the role of family and staff at this time point was initially to assist the participant understand the need for residential care. This was not accepted well by some participants as explored in the first two themes, ‘home’ and ‘normal’. Support with decision making for residential care was a combination of family and staff:

“My daughter and my son both think I won’t be able to cope with home by myself…eventually, they said to me you’ve had more falls and you’ve been home here alone… and if I was not lucky enough to get someone to get me up, I could be here forever… Well, my idea was to get well enough to go home... but this has changed now. So, I decided that I’m going to go to a nursing home… So, I’m slowly coming around a bit.” (P5, m, 68, T2)

The next priority was to identify a residential facility that was agreeable to the participant. One participant had lived in an independent living unit of an aged care complex and was happily going back to the high-level care building of the same venue where she was expecting to meet her previous neighbours:

“It is ok in Kalyra, because two of my neighbours when I was there, a few weeks ago now, are already in their rooms” (P3, f, 97, T2)

Other participants went to visit the new venue:

“I went to the nursing home for a visit, it was very friendly, very open and facilities are great.” (P5, m, 68, T2)

The effect of support for participants moving to a residential facility was psychological support to face the next transition:

“*I see the benefits of having set the goals first. Because then I had a direction of where to go. But the goal changed and I still had a direction to go, and I know where I’m going now” (P5, m, 68, T2)*

“I’ve got to work through to what’s happening with me now” (P5, m, 68, T2)

“(I was) trying to still do the things I was doing before and getting awfully frustrated that I couldn’t do this, I couldn’t do that” (P7, m, 72, T2)

Participants were generally pleased with the level of care they had received in TCP to achieve their goals:

“They stop and listen, most of them, generally they listen and um, I think they are well fitted for the job” (P9, m, 83, T2)

"I've got these people around me that are really worth their crust." (P7, m, 72, T2)

Family and friends' support was seen as essential to immediate and future ability to achieve getting home and staying there.

T3 Social reintegration

By the time of the third set of interviews, the participants reflected back on their goals over the duration of the TCP stay and their gratitude to the TCP staff for their expertise, encouragement and care:

"yes, they were good because they pushed you. I mean, they didn't brow beat you. But they pushed you to your ultimum (sic). 'We will go up the corridor today', you know, 'you can make it'…" (P6, f, 90, T3)

One participant had died since the discharge group of interviews. The other participants had settled back at home or had settled into their new home. In the residential care facilities the physical care support was accepted as part of the daily routine and for those at home, support services had become part of the new routine.

"Somebody comes from ACH and helps every other day with showers, which is good. And once a week, well, once a fortnight, cleaning" (P6, f, 90, T3)

The emphasis of support once home was the reinstatement or establishment of social supports of various kinds. One participant had attained the main goal of going home, although had not achieved any of the sub-goals in order to go home, such as being able to walk, shower, dress or toilet herself, so this was managed through daily services visiting her home. The carers, who provided personal and domestic assistance on a daily basis, also provided the opportunity for a chat:

"I enjoy the company and talking to them. Sometimes I just sit here and, you know, have a coffee and watch the telly and I don't have to talk to them, but if I do, I enjoy it" (P8, f, 82, T3)

Participants each had their family and friend networks reinstated:

"…and I take the opportunity to go in the car and walk around the shops and so forth" (P9, m, 83, T3)

Another participant had started to drive again and was very keen to get out into the community and back to the social activities he had engaged in before the illness, such as going to church groups and visiting his wife in her residential care facility:

"I have got a responsibility while Betty is at the home. I've got to give her some precedence. I feel the responsibility of Betty; she is part of my life" (P2, m, 96, T3)

Participant 9 described sitting in the front garden with his dog, and how the neighbours going past would stop, chat and pat the dog. This meant he was able to re-connect with the local community and experience life beyond his

"..and well, she enjoys it and we talk while they're patting her. That's an outside influence. We talk about things that interest the both of us and so forth, so that's good" (P9, m, 83, T3)

For the participants living in residential care facilities, social contacts were both within and outside the new home. For one participant, it meant visitors coming into the new home to visit her:

"I'm lucky because I have family here and I have friends who come on Tuesday. And on Tuesday, they'll have a wine and the husband always changes the battery in my hearing aid." (P3, f, 97, T3)

Another participant was able to return to an old habit of visiting the local shopping centre for a cup of coffee every week, and having a chat with the regular staff at the cafe. Now he was in a residential care facility, he relied on a friend to go with him in an access cab instead of independently getting there on his gopher:

"And I have one very good friend. He was a neighbour and he comes once a week and takes me to Marion (local shopping centre). Without (him), I would be a lot worse off than what I am now." (P7, m, 72, T3)

Summary

These results explored the participants' perspectives and experiences of goals in TCP and reinforces that goals were not discussed explicitly, that participants yearning was to return home and get back to normal again and how this manifested at the three different time points. The next chapter explores the staff perspectives and experiences of goals in TCP.

CHAPTER 7 STAFF RESULTS

This chapter explores the staff experiences of client goal setting, pursuit and attainment in TCP. Forty-seven eligible staff representing both provider organisations (24 professional staff and 23 assistant or carer staff) were invited to participate. Of these, eight (87% female, all professional staff) participated in three focus groups between the end of September and the start of December 2017. Self-reported age, gender, education and years in clinical practice were collected to describe the sample at the start of the focus groups. The staff from SA health (n = 6) and private enterprise (n = 2) each had a university degree in their chosen profession (Occupational Therapy n = 2, Physiotherapy n = 2, Social Work n = 1, Registered Nurse n = 3). The age range was 26 - 62 years (mean age 41 years, ± 12.7) with professional work experience range from 5 - 25 years (mean 14 years, 7.8) and a range of 0.75 - 7.0 years of experience specifically in TCP (mean 3.9 years, ± 2.9). These data show that the staff who volunteered to participate were experienced in their chosen field with a minimum time of five years as a clinician. Seven of the eight staff (87%) had worked in TCP for more than one year so were familiar with the program and service delivery practices.

Staff experiences of goals in TCP were largely client-centred. Three themes emerged from the discussions: TCP - the language of recovery; Transition – a focus on function; and Challenges with system and processes. These are explored below.

The language of recovery

Goal terminology can be confusing for staff and clients. Goals were identified with clients in the acute setting by staff who worked in liaison, but not in the residential setting. The client arrived in TCP with some goals that the treating team in TCP had access to, but had not identified with the client. Right at the start, the word 'goal' itself was considered too complex for clients to understand:

> *"I sometimes say, 'what do you want to work on? What do you want to get out of being with the program?' because I think if you say, 'What are your goals?' they come back with nothing" (S2)*

> *"I don't use the word 'goal'. I might say 'Where do you see yourself going from here?' I might ask, sort of ask more functional kind of questions like 'What is it you want to be doing? How are you going to be doing that?' I think 'goal' does, is a confusing concept to, particularly to patients that we are seeing, that are in the older sort of age bracket." (S4)*

Staff reported discussions about goals that were initiated as the client arrived in TCP. These discussions were to understand priorities for the client but did not use the word 'goal':

> *"Know what matters to them and what's important to them" (S3)*

These discussions provided a starting point for the client to understand why they were in TCP, what they could or could not do at present to be able to manage at home:

"I think it provides a focus and a guide for not only for the client but for the clinician and so you are working towards the same... thing they wanted to aim for and therefore work on. (S7)

"You can guide what you do, like, clinically" (S3)

The initial conversation on goals also provided an indication of what the staff member could work on and clarify why the client was in TCP.

"Where to start and what the priorities are" (S2)

Staff acknowledged that clients had broad goals, such as going home, and this initial conversation was seen an attempt to break the holistic goal into easier steps to make it easier for the client:

"That's something specific that they need to work on instead of the whole goal because some of the goals can be quite broad" (S4)

"you find that you're actually having to sort of assist and talk through and break down what the smaller goals are to achieve what the larger goals are" (S7)

Therefore, the initial discussions were to assist the client to break down the broad goal into smaller steps, which would become the activities that clients focused on for their therapy in TCP:

"Specifically, really identifying and reinforcing with the client what needs to change in order to achieve the end result" (S7)

This was seen as a means to help the client comprehend their admission to TCP:

"For the patients that are cognitively presenting well, I think it helps them to understand why they are here" (S4)

Staff were not happy with client goals stated as broad concepts because they were not tangible or measurable:

"I think they know what they want but they have problems seeing it as a goal; they want to go home but they don't know, they don't understand the steps they need to go home" (S1) "they definitely see the bigger picture, like, they want to go home, but for them trying to work out how to get home is quite difficult" (S4)

Staff were willing to work only on goals that met the context of the program. The breadth of the goal was considered too big to tackle in the service and need to be broken down into specific steps:

"That's something specific that they need to work on instead of the whole goal because some of the goals can be quite broad" (S4)

This was a challenge for some staff who could not see the relevance of big goals within the constraints of the service, and considered it a waste of time and resources when a client's goal could not be addressed immediately within TCP:

"..not relevant in the sense in the organizational setting, some goals may be relevant only in the community" (S5)

"The client is from Adelaide. One of the goals was to visit Sydney, to visit the family members"

(S6)

Goals that could not be achieved within the program, for example ‘returning to shopping using the community bus’, were dismissed as irrelevant or unrealistic by staff:

“Some goals, I mean, not relevant in the sense in the organization settings, some goals maybe only relevant in the community, so we are limited” (S1)

“..and may not understand that ‘well if I can’t walk, I can’t go and water my garden’. You know, so, we are not going to start working on that until the mobility is safe. So, I think we’re, you know, quite limited in what we can address in this setting” (S4)

This may have been considered in the context of the resources available within the program:

“I think a lot of patients often identify goals that are more based at home and we can’t facilitate that here” (S4)

There was some insight into how this influenced the goals that staff chose to address:

“Which limits the goals or prioritizes them differently I guess to maybe what patients would like them to be” (S4)

The goals themselves were not identified by staff as a measure of whether the client was likely to make it home or not, but rather, likely discharge was termed in the steps required to be achieved in order to get back home:

“That might be something you need to work on, or want to work on, to be able to go home” (S2)

The framework that steps provided was structured to support functional self-care and independence, in a distinctly different manner to an acute hospital approach:

“Sometimes clients feel that in the health system everything's sort of decided for them. This is a way of providing a mix between a clinical recommendation but also giving them some ownership of what that will mean, what they will be achieving for themselves” (S7)

The structure of a step-wise approach to goals was also seen as a means to foster confidence and provide security:

“They are probably not that confident to start from but when somebody’s there, they feel that ‘I’m safe in here so I’m able to do more’…” (S5)

The step-wise approach was considered essential for clients to engage in and work towards their goals but was also seen as a variable - enough to encourage engagement and not too much to overwhelm:

“we try to get the just right kind of framework of, you know, not setting goals which aren’t achievable but sometimes it can be a useful, yeah, moving things along I guess” (S1)

On occasion, the staff used goal non-attainment as a motivator for clients to engage more and work towards their goals:

“You know the idea is for you to go home and be independent, so if you were doing that before, you should be doing it now” (S8)

The goals were written on sheets that were on the wall of the client’s room in TCP. This visible presence was considered supportive to clients; however, clients were not often aware of the sheet and did not refer to it in their interviews. The professional staff interviewed suggested the sheet was available for both clients and care staff:

"..keep on the white board also, so then the carers can point out to the client that 'this is your goal, you are aiming to achieve this goal'. So that can encourage them to get more initiative or participation" (S5)

Conversely, staff identified new goals that were not already on the goal sheet that they discussed with the client:

"That might be something you need to work on or want to work on to be able to go home and then look after yourself, yeah. It's not necessarily something that was written down on the goal setting sheet" (S3)

Revisiting the goals to discuss whether they were achievable was considered important. For clients to identify non-attainment was considered very important:

"After they've talked through their goals and realise what they're not actually achieving, then you can start to see improvements" (S2)

"they actually almost need to be able to see they can't achieve a goal to get into a mind frame of 'oh I can understand now why everyone's telling me that's not realistic'" (S4)

"wake-up call for them to realise 'I need to actually start doing more to achieve what I want or I'm not going to be able to do this'" (S7)

Staff proposed that the motivation to engage in goal pursuit might not be due to a lack of physical ability but more lack of initiation. In these instances, the consistent approach from staff helped the client improve:

"They may not need physical assistance but the constant prompting can make them achieve their goal" (S5)

Articulating the goals were also seen as a benefit for families, as a way to understand what the client was aiming for and why they were undertaking the activities in TCP. These conversations with family also provided a feedback loop regarding progress and discharge planning:

"It's useful for families too, it's used for them see whether somebody is working towards them (goals) or whether they're not going to make it" (S3)

Staff aware of clients' goals were also able to act as advocates for the client when there was a discrepancy between the client and family wishes:

"family that's very aggressive with her, as in the way they speak to her, and um, at first it made her really like 'oh I can't do this' but now I've backed her more, it's like 'I'm going home!'" (S1)

Goal pursuit and attainment was also seen to assist with discharge planning by measuring progress and assisting to evaluate suitability for discharge destination:

"Often at the beginning they are having problems achieving their goals, I'll do a dual pathway (discharge planning for both home and residential care) because I will sit down with and say,

‘if we can’t achieve this or if you can’t develop more skills, we’ll have to think about a facility’” (S1)

Client goals also provided a discussion point in handover between staff, which was beneficial to the team being aware of the goal and what the client was aiming for:

“My handover to the AHA (Allied Health Assistant) would be their (client’s) goal is to be independent, you know, putting their pants on” (S4)

This indicates that staff discussed ‘goals’ with their colleagues, but ‘recovery’ or ‘function’ with their clients.

Transition - a focus on function

Functional improvement was aligned with discharge, and the type of goal in TCP generally related to physical function. As the TCP premise is to improve functional status, there is little surprise that physical function was the main descriptor for the clients’ goals. Goals were not considered ‘autonomous’ items by staff, but more general functional activities such as showering, dressing, walking, managing medication or making meals:

“Daily living is the majority, main focus.” (S2)

“Therapy here is very based around daily activities” (S3)

“The physio sees them three times a week, the OT sees them for breakfast assessments and kitchen assessments, and shower assessments, they’re all sort of goal focused” (S8)

Improving function was considered important for all domains, whether or not the client had identified that domain as a goal area or not:

“We had one lady last week who had no physio’ goal whatsoever listed but she was still needing, you know, plenty of therapy” (S3)

“The carers, they usually help them for shower and the personal hygiene assistance, so, we asked them to document, um, like what they are able to do, what they are not able to do” (S5)

This focus on functional activities was considered different to the care provided in the hospital setting and a necessary focus in the transition from hospital to home:

“They often come from hospital where everything is done for them and it’s a very different frame of um everyday expectations here than what it would be where they previously were” (S4)

The implicit approach to goal pursuit through functional activity was not articulated well with clients because it was assumed:

“It’s like an ongoing process from the first day of admission” (S5)

The assumption led to staff merging the goals and functional activities as the same thing:

“Some of the goals can be improved or pushed a little bit up with their daily activities. The other way, when they improve, I mean, when they are aiming for or achieving their goals, that can help them to improve their daily activities” (S5)

Feedback on goal progress was therefore considered an inherent part of feedback on the functional activities, rather than being distinctly related to goals:

“day to day therapy too, we are giving constant feedback and might not be actually mentioning the words goals but giving feedback about, yes, you’ve improved in this or we’re still working on that” (S3)

Steady progress toward goal attainment was considered by staff to provide a sense of achievement for clients.

“You know: ‘I need to walk a certain distance’ and they know that they need to walk a certain distance, and most of them know they have to walk a certain distance in order to be independent” (S6)

One staff member expressed it as identifying and addressing the gap:

“We know clinically they can't go home, but they may or may not realise that themselves. I guess it's just really nutting down what needs to change in order for them to go home” (S7)

However, this all-encompassing approach does not account for any personalised goals:

“I think when they continuously practice the daily routine, they are achieving” (S5)

Staff were concerned that cognitive impairment influenced client insight regarding functional ability, and then relating the functional ability to attaining goals:

“There’s specific goals you need to pass before you go home and before we know you are ok to go home. And I think some of them do have problems comprehending that” (S1)

“I still find that some people are quite disconnected to their goals, even though they’ve been through a process of setting goals, you know, it’s almost ‘that bit of paper over on the wall’..” (S3)

“Because of her condition, she’s denying and denying, saying, ‘I can do, I just want to go home’. Then we have to tell them ‘you need to achieve this goal before you go home’. And the next day, she’s still doing it, and still depending on the personal carer to go to the toilet, and help her” (S6)

Staff sometimes considered clients’ cognitive decline to be a barrier to goal identification and pursuit. Likewise, staff may have held some prior beliefs about the general capability of older adults to engage actively in the goal setting process, or to make their own minds up about decisions in rehabilitation:

“When you getting old, your cognition getting older, you can’t make a decision” (S6)

Conversely, clients without any cognitive or communication concerns might state goals that the staff considered ‘inappropriate’ or ‘unattainable’. This caused concern for balancing client-centred care needs with professional duty of care:

“they legally have the right to choose whether they follow our advice or if they don’t follow our advice, even if we do everything we can to legally, and morally and ethically follow our practice, they still have that right” (S8)

The staff considered the relative age and frailty of this client population had implications on cognitive or communication ability to discuss recovery and functional improvement. The population of TCP clients was seen in itself to be a challenge due to TCP clients being aged 65 years and over and having multiple co-morbidities, therefore many of the clients were considered frail on admission:

“But depends on the condition, probably that goal is unattainable because of the client’s condition so there are, like that, so there are some goals which are unattainable” (S5) “old people always take more time to get stronger” (S6)

“It may look good from the start but because they are so elderly and frail, it can all fall in a heap and you’re back at square one” (S8)

Staff perceived that clients struggled with change, such as renegotiating goals or identifying new goals:

“re-evaluate the goals was seen to be sometimes challenging... this population can, like, can really struggle with the ‘shifting goalposts’ aspect of things” (S7)

“They’re very set in their ways most of them and you know, you’re just trying to unclutter somebody’s house or get them to move a rug. It’s just a huge issue isn’t it?” (S8)

Change provided challenges for clients to participate. Staff perceived the challenge to be exacerbated by a reduction in memory function:

“It’s their decision, but they may forget” (S5)

“The patient, when they come here, they don’t feel that is a goal for them, or they forgot they make that goal” (S6)

The functional activity focus is an inherent part of the transition between hospital and home; however, individualized goals are lost within the generalist approach. Other barriers to goal pursuit and attainment are considered in the next section. These are separated into client and system barrier sub-themes.

Challenges with process and system

“They come to TCP. We solve the problem and, set to go home” (S6)

This comment speaks to an overall consideration that the client improves and is able to go home, but the underlying tone demonstrates that staff ‘own’ the goal, not the clients.

The ‘we’ in this statement suggested a team that did not include the client. Client goals were discussed formally in a weekly meeting between the professional staff, but excluding the client, the carer and allied health assistant staff:

“We review everyone’s goals at the case conferences” (S2)

At the time of this research being conducted, new case manager roles had been instigated within the professional team. A case manager was allocated to each client and became the central liaison person for the client in all aspects of their care within TCP. The case manager role was described as:

“The case managers talk to the clients about their goals, how they’re progressing, if the goals need to change, or evolve… Case management role is just to oversee that the appropriate disciplines are involved that need to be involved to address the goals…” (S2)

The team met weekly for case conference. Case conference was seen as an explicit opportunity for the professional staff to come together and discuss the client goals, their progress toward them and their subsequent progress towards discharge, but did not necessarily include the client in the discussions. Additional concerns, new goals, additional input from other disciplines or a more structured approached therefore might be considered at this time:

“that might prompt us to get other clinicians involved that haven’t been previously… then the case manager would say the goal and then you’d give an update and, sort of, that is where you might say formally to the team ‘actually things aren’t going so well, this is what we’re thinking’..” (S4)

“We might find another goal to put on there, you know? If something else hadn’t been picked up or becomes out of the discussion, we might put it on at that point.” (S4)

“Who else we might need to involve to actually achieve that, whether its community supports or family or and start to have those conversations really early” (S4)

The middle example confirms the ownership of the goals belonging to the professional staff who ‘find another goal’ on the client’s behalf. Progress discussions with the client were considered the domain of the case manager. When concerns arose regarding goal non-attainment, that is, lack of functional improvement and therefore inability to return home, the initial approach was to instigate a conversation between client and case manager:

"often, the idea is that the case manager then goes back to the client and has that discussion about ‘This is what the chat was at case conference’ more often than not, and goes through their goals again which are kept in their room and I guess sort of talk about where they're tracking” (S8)

Other staff confirmed this was the approach:

“if you know they are not able to do it, that’s when you do more counselling, talk to your team and often will bring the social worker in and communicate with them” (S1)

Some of the system challenges included assessing clients on performance in the service when the facilities and layout were unfamiliar. This presented an unfair appraisal of goal attainment or failure:

“some of the goals, like a kitchen assessment, it’s a fail here but when he goes home you know, he’s been doing 30, 40 years, he knows where it (the kitchen item) is, but you go to this kitchen (in TCP), you don’t know where is the coffee?” (S6)

Professional staff were involved with formal goal conversations through case conferences, but the staff that spent the majority of the time with the client addressing the functional activities were not formally involved in these conversations. Informing and sharing information with the whole team, including allied health assistants and carer staff

> *"if you were really wanting to make it completely, and this might be unrealistic, but client-centred and client-focused and everyone contributing towards the client goal, whether maybe down that low end, the on-the-ground day-to-day staff, with a bit more input and involvement from that end, might actually, yeah, assist the program generally" (S7)*

Summary

This chapter explored the staff experiences of client goal setting, pursuit and attainment in TCP. The language of goals was not explicit in TCP and the focus was on functional recovery and daily activities rather than goal pursuit. Challenges were identified for clients concerning their co-morbidities, frailty, and potential for changed cognition, and for the service, especially the limitation of what was achievable in the constraints of the facility. The relationship between client and staff experiences will be explored in the next chapter.

CHAPTER 8 DISCUSSION

This research explored the older person and staff lived experiences of goals in TCP to investigate whether processes and outcomes were person centred. This chapter explores the congruence and differences between participant and staff experiences of TCP goals and the alignment of these findings with the literature.

Participants were admitted to TCP because they were unable to go straight home as expected from the acute hospital where they had been admitted for a new medical or surgical event (Grill et al., 2005). Limited recovery from that event had left them at a functional level that did not permit an immediate return home (Baztán et al., 2009). TCP liaison personnel worked with participants in the acute hospital to identify goals for TCP. At the admission interviews, participants reported their goals broadly as getting better, going home and returning to normal. Participants saw their goals as necessary to strive for independence, self-belief being the motivation to get home and back to normal. This aligns with the goal setting literature regarding self-belief being core to goal pursuit in the community (Bodenheimer & Handley, 2009) and rehabilitation (Levack et al., 2016). Autonomy and self-belief were similarly identified in this study's systematic review of patient experiences of goals across health services (Wressle et al., 1999). Older adults are more likely to engage with goals if there are motives such as enjoyment, satisfaction or progress (Aberg, 2008) which connect with the person's identity and self-belief, based on the theory of self-determination (Ryan & Deci, 2000b). Self-belief was challenged in clients when they encountered doubt or uncertainty, particularly when they thought they were not progressing or may have been unable to go home.

On arrival in TCP, participants were uncertain of a number of things. They were unsure of the time that would be required for recovery from their illness and this included uncertainty of the level of recovery required to return home. Participants entered TCP with the clear goal of returning home, but were unsure how long it might take to get there. Participants were also unsure whether they would get back to normal, how long that would take and whether it would occur at all. In addition to the uncertainty, the participants were exhausted from the physical deconditioning effects of the illness causing hospital admission in addition to the secondary deconditioning from prolonged hospital stay (Koenig et al., 1999). This self-doubt is incongruent with staff experiences of using non-attainment as a facilitator to engage and motivate the clients and deserves further investigation.

Only 25% of the admitted clients between 5 September and 30 October had the interest, energy, cognition and communication skills to discuss their goals with this researcher, which speaks to the effects of mental and physical fatigue felt by all clients admitted to TCP and aligns with the findings of the systematic review in this thesis. Bailly et al., (2014) identifies that the ability to adjust to change correlates with overall life satisfaction (Bailly et al., 2014). The object of change differed between participants and may have included loss of identity, functional independence, driving capacity or ability to live at home. The need for adjustment was consistent but the degree differed, as did the stage of grief that participants displayed in their interviews. All the client participants recruited in this research were able to communicate effectively and were cognitively intact. However, even they commented on feeling muddled or unable to articulate themselves as effectively as usual after their acute hospital stay. The impact of grief and the additional psychological and emotional effects of fatigue may explain why this population found dealing with change so difficult.

Consistent communication

Staff described a review of participant goals on admission to TCP, suggesting that this discussion provided a common starting point and shared vision for clients and staff to work on together. This principle aligns with the goal setting literature regarding the benefits of goal setting to engage the patient (Hoffman et al., 2018) and sustain behaviour change (Kwasnicka, Dumbrowski, White, & Sniehotta, 2016). However, the participants were not aware of these conversations being specifically about their goals. In fact, participants suggested that 'goal' conversations did not necessarily occur at all during their stay in TCP. Participants considered staff encouraging and supportive of functional daily activities but did not relate these activities to their goals. Staff integrated daily functional activities into measures of progress and discharge planning. However, the activities were not named explicitly as 'goal' pursuit, so the participants could not see the relevance of daily activities to their goals and did not believe they had had conversations about goals with the staff.

The discrepancy was most likely due to the language of recovery and focus on function that the staff used with participants, specifically avoiding the term 'goal', which sets up for ambiguity and is contrary to the values of shared decision making (Elwyn et al., 2012). These contrary experiences of the reason for the same daily functional activities reinforce the need for consistent, explicit language regarding goals (Plant et al., 2016; Sugavanam et al., 2013).

This reinforces the findings by Taylor et al., 2012 of making the understanding of goals unambiguous to avoid confusion and to maximise engagement (Taylor et al., 2012). The consequence of this lack of shared understanding was that the participants were not sure why they had set goals when they were never discussed, and were unclear how the goals they had set were related to going home. These experiences of inconsistencies with care and therapy provision are not congruent with principles of open communication and person engagement for person centred care, which intends to place the person's needs and wishes at the centre of the interaction (Epstein & Street, 2011).

While some participants were grateful for practicing walking, showering or making meals, other participants felt the activities were less intense or frequent than they had expected. The focus of participants and staff was to celebrate small as well as large gains in functional ability. Both groups agreed that it was important to acknowledge small gains as they occurred, and this is consistent with the findings by Brown et al., (2014). Staff saw improvements in functional daily activities as equivalent to goal attainment. There is potential for staff to assume that all client goals are the same, based on functional recovery (Schulman-Green et al., 2006). This does not align with the literature that support individualised goals for a person centred approach (Kitson et al., 2013). Staff identified that not making progress was a stimulus for clients to work in a more determined or directed manner which aligns with literature on goal adjustment (Bailly et al., 2014) but not the participants' experiences, as stated previously.

Frequency of re-visiting and reviewing goals was not explicit in the literature (Stevens et al., 2013). In this TCP, staff discussed client goals with other professional staff in the weekly case conference discussions. Discussions at case conference did not involve the participants, nor the staff who spent the majority of time with the clients, namely carers and their allied health assistant colleagues. Whilst a team discussion aligns with the evidence for collaborative practice (Gilbert, Yan, & Hoffman, 2010), these participants were not involved in these conversations about them, and only made aware of decisions or outcomes when the case manager relayed the discussions back to them. This indicated that the participants were not active in the choices or decisions for their own progress or discharge planning, which is counter to shared decision making principles (Elwyn et al., 2012) and person centred care (Epstein & Street, 2011). These results do not match the recommendations in the literature on explicit communication regarding goal processes (Sugavanam et al., 2013). This gap in collaborative practice is not person centred and provides an opportunity for a review of communication systems in this TCP.

At discharge, some participants were very pleased to have attained their goals of going home; however, those participants discharged to a residential care facility expressed disappointment, anger and grief for their losses of independence, home, routine and identity. Discussions regarding transition to residential care can be assisted by time for consideration, shared decision making and client education (McKenna & Staniforth, 2017).

The diverse terminology and lack of clarity with communication was identified as a barrier by staff although staff restricted meaning for this to client communication or cognitive deficits (Hersh, Worrall, Howe, Sherratt, & Davidson, 2012; Levack et al., 2014).). The participant cohort in this study had no cognitive or communication impairment, however they comprised only 25% of the total clients admitted to the program during the recruitment timeframe; the remaining 75% declined or did not meet admission criteria, including cognitive or communication deficits. Goal identification and pursuit for all clients in all health services is important for engagement, motivation and participation (Barnes & Ward, 2005). Further research into methods that enhance engagement, motivation and participation in goal setting and pursuit for clients with cognitive or communication deficits is warranted.

Home

For participants and staff, the main driver for all activity was aiming for home. Home provided the motivation for participation and striving for independence for participants. The drive to be home was a consistent stimulus yet individual motivation to be home varied. For some participants, as previously reported in the systematic review, it was the return to ‘normality’ and usual routine (Gorawara-Bhat et al., 2008; Kuluski et al., 2013; Melville et al., 2002; Pikkarainen et al., 2018; Schellinger et al., 2018; Schulman-Green et al., 2006). For others, ‘home’ meant reconnecting to their community and loved ones, which is established as being essential for mental wellbeing, feeling connected and avoiding loneliness (Cornwell & Waite, 2009). For yet other participants, home identified the end to illness, hospitals and external care routines and reinstated the person’s autonomy and self-efficacy (Huijg et al., 2016). The goal of ‘aiming for home’ was essential to the participants’ usual sense of identity in addition to providing hope for the future (Coylewright et al., 2016, Schellinger et al., 2018).

Home represented more than bricks and mortar for participants; it represented sanctuary and familiarity in a tumultuous and challenging time. The yearning to return to the safety and security of home was an intrinsic motivator to participants. Intrinsic motivation is defined by self-belief and a sense of identity (Jones & Riazi, 2011). The participants identified different meanings to self-belief. For some it was to be independent without help, for other it was to be able to perform daily activities and self-manage without external assistance. Self-belief contributes to self-reliance, which is essential to progress through goal related activities (Efraimsson et al., 2006). Staff reported that participants enhanced their engagement and participation in daily activities and therapy sessions when they were motivated to go home (Jones & Riazi, 2011). Extrinsic motivation is the measure of progress towards a goal (Ryan & Deci, 2000a), described by the participants as their reliance on family support and staff expertise. Staff took the responsibility of identifying the steps required to achieve a return home, by considering the client’s current physical and cognitive functional abilities. Staff attention to the client’s health condition, current function and likely prognosis provided the structure for clients to work toward getting home (Brown et al., 2014; Hjelle et al., 2017; Pikkarainen et al., 2018).

Transition care program is designed to support and assist clients to rebuild lost function to return home and avoid unnecessary residential care admissions (Gray et al., 2008). When they reflected on how ill they had been, the participants identified their primary goal had been to get back to normal. Gaining medical stability and moving to TCP had meant the goal of survival had been surpassed by motivations for recovery and return home. As the participants improved in their functional ability, so did their self-belief increase. This aligns with the findings of Brown et al., (2014) who described the transition in thinking for rehabilitation patients from survival to autonomy (Brown et al., 2014). Older adults are more likely to be motivated to engage with transition programs if they are well-informed of the potential benefits and believe the program will assist their ability to recover, return to normal and get home, thereby tapping into their self-efficacy (Hawkins, Wells, & Hommer, 2014).

Throughout their TCP journey, participants identified psychological and emotional support from family and friends. The frequency and intensity of support provided by family was the decider for discharge destination: one participant had no support from family members, was unable to be independent overnight when formal carer services were not available so discharged to residential care. A second participant was similarly restricted with functional ability, but her son lived at home. This participant was able to discharge to her own home, not to residential care. Limited social support is identified as a flag to unsuccessful transition from hospital (Jacob & Poletick, 2008) so this finding is consistent for successful transition home. There is congruence with staff observations that engagement and discharge planning was enhanced when the client had supportive family members involved in their program.

All participants required ongoing support from formal or informal sources on discharge from TCP. Those who discharged to residential care were reliant on the new residential facility staff to provide assistance for daily functional activity. The participants who discharged to their own home were reliant on families, in addition to health practitioners or care staff from community services to provide daily assistance once home. The ability to foresee themselves in the future was a construct of participants' self-belief, which aligns with the systematic review findings of being able to look forward with hope (Brown et al., 2014, Coylewright et al., 2016).

At three months post discharge, other than the one participant who had died, the participants were settled at home or settling into their new home, which underpins the importance of home to identity. Social reintegration at this time explored contacts with family, friends, carers, neighbours and the local community. Social contact is essential for good mental health and wellbeing (Tough, Siegrist, & Fekete, 2017) and therefore these experiences support the participants on their restorative and healthy ageing pathway (Chen et al., 2012).

Participants identified barriers that affected their ability to engage and participate in daily activities, namely fatigue and uncertainty. The greatest barrier reported was mental, physical and emotional fatigue. Fatigue is established as a symptom of frailty (Morley et al., 2013) and has been described as a barrier to engagement and motivation (Brown et al., 2014, Efraimsson et al., 2006) impacting patients' ability to engage in goal-related activities. Staff acknowledged the physical aspects of fatigue in relation to the likelihood of these clients being medically unstable, potentially returning to hospital, being frail and feeling too tired to participate. In the hospital setting, frail elderly tend to stay longer due to complications and co-morbidities, which reignite the functional decline cycle (Iwashyna et al., 2010). While staff had acknowledged physical fatigue, they had not acknowledged the psychological or emotional effects of fatigue, which affected the participants' ability to take in and process new information, to maintain motivation, to engage and to participate in daily activities or therapy sessions. Fatigue was an ongoing problem for the participants and continued throughout their time in TCP and beyond. The psychological aspect of fatigue and weariness was associated with a fear of illness or sickness returning and a fear of becoming dependent that continued well after discharge from the program. At three months, fatigue was still cited as a problem and an ongoing barrier to engaging back in usual activity or the community. Although fatigue and has been researched in relation to specific conditions such as Multiple Sclerosis (Kos, Kerckhofs, Nagels, D'hooghe, & Ilsbroukx, 2008) and cancer (Cramp & Byron-Daniel, 2012), there is limited evidence for the impact of fatigue on motivation, engagement and participation in rehabilitation or restorative care, and therefore warrants further research. Additionally, staff education on the psychological and emotional effects of fatigue may assist a more person centred approach to the service. The complex nature of fatigue affecting so many aspects of life may also explain why so many potential participants chose not to engage in the research at the time of recruitment.

Uncertainty provided another barrier to engagement and participation in goals. Participants reported they felt overwhelmed when they arrived in TCP with new layout, staff, routines and systems. The participants' lack of preparedness for their initial illness, the move to TCP and the unpredictability of their progress was overwhelming. Feeling overwhelmed could be addressed by reassurance, explanations regarding prognosis and an individual person centred approach (Simmons, Wolever, Bechard, & Snyderman, 2014).

Both participants and staff identified structural concerns. Participants identified concerns with feeling socially isolated in their single rooms. This population of frailer, older people were at TCP to improve their functional mobility and were often unable to mobilise independently or for sufficient distance to exit the rooms independently. This meant they were less able to engage with the many activities on offer. The reliance on family or staff to take them out of their room influenced their independence and autonomy. Social isolation is associated with poor mental health (Cornwell & Waite, 2009) and contrary to the intent of TCP which aims to enhance physical, cognitive and social function (TCP guidelines, 2014). Other structural barriers identified by participants were the reduced access and inefficiencies with therapy sessions particularly with lack of exercise intensity, and the perceived impact of this on participants' recovery.

Staff identified additional structural concerns, which included unsuitability of assessing domestic functional tasks in an unfamiliar environment for clients with cognitive deficits. This has been identified as a concern in the literature, where outcomes may be inconsistent, or even unfair, considering assessment outcomes inform discharge destination (Taylor, Broadbent, Wallis, & Marsden, 2018).

Staff identified difficulties with goal adjustment when the client had communication or cognitive deficits and this is consistent with the literature on barriers to goal setting in rehabilitation settings (Laver et al., 2013). Staff regarded this population as relatively inflexible, having difficulty managing change, whether it was for home set up or discharge destination. Reduced cognition in clients affected their safety with a reduced capacity to problem solve or make informed decisions, according to staff. This may indicate an opportunity for staff development on shared decision-making principles where the client and staff together explore the various options available (Elwyn et al., 2012).

The literature identifies additional structural concerns not identified by the participants or staff. These relate to restricted time availability for goal setting (Leach et al., 2010), lack of staff expertise (Scobbie et al., 2011) and the necessity of funding pressures of time or funding to drive treatment (Levack et al., 2011, Rosewilliam et al., 2011). Further exploration of the system barriers in TCP is warranted. The above discussion identifies TCP processes for goal attainment, how goals are incorporated into clinical interventions and how goals inform discharge planning. There is different meaning between participants and staff with goal identification, pursuit and measuring attainment.

Summary

Many of the findings in this research align with the literature including intrinsic and extrinsic motivation and self-belief being facilitators and inconsistent language and poor communication being barriers of goal setting and pursuit. There are also consistencies with staff deconstructing the participants' broad goals to meet organizational requirements.

Discrepancies arose with staff naming goals and measuring attainment by functional activities, which was not explicit to the participants. Likewise, the overwhelming fatigue that affected participants was acknowledged only as physical tiredness by staff.

These areas of discrepancy will be explored further in the next chapter that identifies recommendations for clinical practice, health policy and further research.

Limitations

Limitations to this study include the bias of the participants who self-selected for the research, and the limited number of participants describing their experiences of transitioning to a residential care facility. There are also limitations with the exclusion of carer and assistant staff in the staff demographics as they provide the majority of contact with the clients in TCP. Their perspectives and experiences would have been greatly valued and may be an area for future study. Likewise, being unable to gain the experiences and perspectives of clients with cognitive or communication deficits provided a natural bias toward clients who were willing to talk and share their experiences.

The research was conducted at a residential TCP site in a metropolitan area of South Australia for convenience and therefore does not include community TCP or rural perspectives, which may differ.

CHAPTER 9 RECOMMENDATIONS

This research investigated client and staff lived experience of goals in TCP, which explored the understanding, processes and outcomes related to goal identification and pursuit. The consistently reported goals throughout participants' stay in TCP and beyond were 'home' and 'normal' although explicit conversations about these being goals were not undertaken. 'Home' and 'Normal' were considered to be too broad to measure attainment by staff, and the goals were broken down into measurable steps that could be achieved within the context of the TCP service. There was congruence between participants, staff and the literature with commonly identified facilitators and barriers to goal setting and pursuit. Furthermore, there were discrepancies between participants, staff and the literature, which inform clinical, health policy and research recommendations. The results identified opportunities to facilitate person centred care and enhance shared decision making in the clinical setting of TCP.

Clinical recommendations

The first clinical recommendation is to establish formal discussions regarding goals with the client as soon as they enter the TCP. This would make a connection between the daily activities and provide the initial shared decision making regarding goal progress and attainment, particularly in relation to discharge planning. Subsequent frequent discussions would engage clients in decisions about their care, clarify goal progress and assist to identify discharge plans more explicitly. Goal discussions could be enhanced by incorporating carer and assistant involvement, as this group in the workforce have the most frequent contact with the client. Incorporating this staff group in discussions would capture functional levels and regular progress and support the next steps with the client, and therefore inform plans to share with the entire team. A system that captures these considerations would make the communication explicit, incorporate the clients' active voice in decisions about their care and be available to the entire team to promote person centred care.

A second area for clinical recommendation is the change in staff perception of what an acceptable or attainable goal might be. The participants described broad, holistic goals. These were broken down into smaller steps by professional staff. The steps, rather than the holistic goal, became the measurable item for staff to identify goal attainment within the constraints of the TCP, thus denying the client's ownership of the goal. Affording measurement of steps towards a holistic goal would need a paradigm shift in thinking for staff but would enhance a more person centred approach to the services provided.

Health policy implications

The implications for health policy align with the KPIs for TCP. At present, client goal attainment is measured in binary form – met or unmet. Attainment or non-attainment has no current connection to discharge destination, or the KPIs of bed occupancy, LOS, discharge destination, up-transfers or mBI. Identifying an association between goal progression and the client's functional change, such as changing the functional measure from mBI to something more sensitive, or using a formal, structured tool such as GAS to identify and measure goals, would evaluate the program's effectiveness in functional restoration in a more objective manner and therefore identify the relationship between goal attainment and TCP effectiveness.

Further Research

The implications for further research are firstly to investigate goal setting, pursuit and attainment for older adults with communication or cognitive deficits. This sub-population is often excluded due to concerns with providing informed consent and the ability to participate in the research. However the population continues to age and this sub-population need an authentic way to be included in shared decision making. Identifying processes that enhance engagement and participation would ensure person centred care and enhance community consumer directed care.

A second area for further research is the investigation of psychological, emotional and physical effects of fatigue on motivation, engagement and participation in rehabilitation and restorative care. Fatigue was identified as a barrier to goal setting, pursuit and attainment both by participants and in the literature. The effects and impact of fatigue warrant further investigation in this and other populations.

A third area for research would be the translation of findings to clinical practice based on a staff intervention to change the implicit language and associated daily activities into explicit goal identification, pursuit and attainment. An intervention with staff could also investigate means to reduce the barriers identified in this research, i.e. social isolation within the service, fluctuating intensity of therapy, managing client fatigue and uncertainty. It would simultaneously enhance the facilitators of explicit communication and feedback to measure goal progress and attainment.

APPENDICES

1. Systematic Review search strategy
2. Ethical approvals
3. Flyer
4. PICF client
5. Staff sign-up sheet
6. PICF staff
7. Staff demographics
8. Interview Schedule

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