Life goals in residential rehabilitation: interpretive phenomenological analysis of the experiences of people with complex acquired brain injury.

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Abstract

Background and purpose
There is the need for research exploring goal adjustment processes in the context of complex neurological impairment. This is particularly evident for people with cognitive and communication issues who have a limited voice within the body of life goal literature. This investigation explored the experience of people with complex acquired brain injury, regarding the role of life goals within the context of being a recipient of residential rehabilitation services.

Methodology
Five people (three women and two men) with acquired brain injury (ABI) were interviewed using semi-structured interviews. These interviews were recorded, transcribed and subject to Interpretative Phenomenological Analysis (IPA).

Results
The supraordinate themes emerged capturing how participants’ perceptions of the facilitators and barriers to life goal achievement were connected and dynamically balanced. Within the results there was a strong emerging theme related to the importance of social connectedness. This was reflected in first theme ‘Being part of things’ and was related to the desire for all participants to be actively integrated, connected and encountering within their social relationships and as citizens of the world. The other two themes referenced a dynamic interplay existing between interpersonal factors related to an ‘Unchanged, changed and changing’ self, and the presence or absence of ‘Opportunities arising’ in the participants’ milieu.

Discussion
Participants’ narratives in the present study support a growing body of literature highlighting a need to focus on the role of social identity and the environment in the delivery of person-centred rehabilitation services for people with ABI. If we are to
support people to achieve their life goals following a severe ABI, then we will need to continue to develop theoretical frameworks and interventions that better support people in terms of social relationships and social identity throughout their lives. There is also a need to be aware that the person’s milieu is susceptible to change even after severe ABI and that people in residential care following ABI require increased environmental support and creative solutions to facilitate life goal attainment. Recommendations for providing a rehabilitation service that can better support people to live well with a brain injury throughout their lives include the following: regular, in depth and open discussions in which individual’s values and preferences are discovered; a focus on facilitating coherence between daily activities and the person’s life goals; and consideration of how an individual’s life goals change and are reprioritised over time. Attention to life goals will allow future research and theory to be more representative of, and responsive to, the experiences of people who need to access services and support following an ABI.
Acknowledgements

No man is an island
(John Donne)

No man is an island,
Entire of itself.
Each is a piece of the continent,
A part of the main.
If a clod be washed away by the sea,
Europe is the less.

For me this thesis represents the significance of being connected and integrated within a supportive community – a group of people who have facilitated the creation of an environmental niche allowing me to develop as a researcher and a clinician. I am indebted to you all.

I am very grateful to my supervisors, Dr William Levack (PhD) and Ms Anne Sinnott (MPhty). Your wisdom, experience and support have been invaluable. I have appreciated your enthusiasm and willingness to embark with me on my journey towards being a researcher.

A profound sense of gratitude is offered to the participants in this research who were able to contribute to me personally, and to the wider rehabilitation community, through the sharing of their stories. I have been privileged to listen and learn from you.

Dr Fiona Graham has also provided amazing support. This support has been both in her clinical advisory role within this research but also as a supporter of my tentative steps into conference presenting and journal paper writing. It has been incredibly helpful to talk through the issues that arose within the interface of my clinical and researcher roles. Thank you.
The residential facility management, and my clinical colleagues, have provided significant support for me in this research endeavour. This has included financial support, encouragement and practical assistance, and for this I am incredibly grateful. The many open discussions within the clinical environment have contributed to my thought processes and helped me to question my assumptions. A special thank you to Pip for her friendship and loving encouragement.

Friends, who have encouraged and supported me to explore some of my questions, also form an important part of this niche. Thank you to Catherine, Kathy, Donna and Helen for your friendship and for the parts of life that we share.

Watching my father survive and thrive following an ABI has been inspirational. Dad, you have taught me so much – both as a daughter and as a therapist. Thanks to you (and Mum) for your ongoing love and wisdom.

Finally, thank you to my family – to Mike, Ella and Hamilton. You have been patient, encouraging and kind. But you have also continued to demonstrate on a daily basis what a sense of belonging can look like, and how it can positively affect my wellbeing! I am forever grateful.
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<th>Description</th>
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<tbody>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
</tr>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebrovascular Accident</td>
</tr>
<tr>
<td>EPOA</td>
<td>Enduring Power of Attorney</td>
</tr>
<tr>
<td>EU</td>
<td>End User</td>
</tr>
<tr>
<td>GOALS</td>
<td>Life Goals Questionnaire</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>IPA</td>
<td>Interpretative Phenomenological Analysis</td>
</tr>
<tr>
<td>RLGQ</td>
<td>Rivermead Life Goals Questionnaire</td>
</tr>
<tr>
<td>SWB</td>
<td>Subjective wellbeing</td>
</tr>
<tr>
<td>TBI</td>
<td>Traumatic Brain Injury</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
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</table>
1 Background

1.1 Setting of the research

This investigation aimed to explore how people with ABI, in a residential rehabilitation service, experienced life goals. At the time of writing, the residential rehabilitation facility in which this research was undertaken incorporated 41 slow-stream rehabilitation and long-term residential beds for people with physical, cognitive and sensory impairments. Two-thirds of the residents at the facility had an acquired neurologically-based injury, and one-third had congenitally acquired impairments. Approximately 12 clients within the facility were funded on rehabilitation contracts. This incorporated people who required input over a period of as little as three months, through to those who required ongoing input throughout their lives.

The residential facility includes a variety of housing options. The main building includes 25 bedrooms positioned around a centralised living and dining area. The wing where the majority of people undertaking active rehabilitation live also includes a kitchen and gymnasium for use by the residents as a part of their individualised programmes. Five one-bedroom self-care units, which allow people to live more independently, are also situated within the complex.

There are also two environmentally distinct areas in the facility operating within an Active Support model of care (Stancliffe, Jones, Mansell, & Lowe, 2008). These are essentially physically separated cottages where between four and six people live together in a small group living situation. Active Support is a widely used and researched approach to specialised caregiving by frontline staff working with people (often with intellectual disability) living in residential care homes. The Active Support model of care is a particular interaction style that staff utilise with residents. Residents’ choice and control over their daily schedule and their environment is paramount. The principal aim of Active Support is to increase resident engagement in meaningful activity. The first Active Support environment was set up in 2009 in a standalone house within the residential facility’s grounds. A recent study (Graham, Sinnott, Snell, Martin, & Freeman, 2013) explored the experience of stakeholders engaged in Active
Support within this cottage. I performed the role of key informant, participated in the allied health focus group and assisted the research team to identify key stakeholders and to understand contextual and historical influences on the implementation of the programme. The research skills that I gained, and the critical reflection I engaged in through my involvement in the Active Support study, have richly contributed to the development of this investigation. Through this current body of work I have continued to question how best to facilitate meaningful lives for people with complex disability who require residential rehabilitation support.

1.2 Clinical background

I am the only physiotherapist working within the residential facility and am employed to work 20 hours per week. My role has been on both a contracting and employment basis over a period of eight years. The role that I provide is broad. Essentially I work as an interdisciplinary therapist with my key clinical colleagues, an occupational therapist and a social worker. The model of service delivery at the facility means that while I assess and oversee the people undergoing rehabilitation programmes, it is a rehabilitation coach who delivers the activities that support the programmes on a day-to-day basis. My clinical role is essentially more of a programme coordinator, planner and evaluator. I also have a key-professional role with around ten people who are on rehabilitation contracts. This means that I am responsible for ensuring that their programmes are both centred on their self-identified goals, as well as meeting the requirements of the rehabilitation funder. Over the past four years I have been working towards my Master in Health Science on a part-time basis. This has occurred in conjunction with the clinical role that I have within the setting of this research.

I graduated as a physiotherapist in 1991, and since this time I have principally worked in the field of rehabilitation – either with people after a neurological or cardiac event. I have worked in an acute neurosurgical setting, a secondary-care setting, in the community and in a residential context. I have also journeyed with my father after he sustained a severe ABI in 1999.

My interest in the topic of this research arose through reflection on how to best meet the subjectively perceived needs of people with life-long disability who require
ongoing 24-hour support. My clinical experience has provided me with preconceived notions about the content and delivery of rehabilitation services for this population. Reflective consideration was therefore given to my preconceptions at all stages of this research process. Reflections on my dual role in the process of data collection and analysis, and how this may have impacted in the final narrative account, were maintained in a journal and discussed with my supervisors. A clinical advisor role was also established to allow me to discuss and reflect on ethical issues as they arose. Further discussion around these issues is covered in section 3.6 of this thesis.

Through the process of this research I have been challenged to consider the breadth of my professional role, the significance of the organisational structures that are in place within health and disability services, and the importance of explicitly seeking to hear the voices of the people we aim to support through these services. I have also developed an understanding of the responsibility required of ethical research.

1.3 Research aim

This investigation aimed to explore the lived experience of people with complex acquired brain injury (ABI) regarding the role of life goals within the context of being a recipient of residential rehabilitation services. The research question was motivated by the need to include user perspectives in the evidence base supporting rehabilitation service delivery. It is hoped that the results from this work may contribute to these services being more representative of, and responsive to, the experiences of people who need support and rehabilitation following an ABI.

1.4 Definition of key terms

*Acquired Brain Injury*

While there are many conditions that can result in neurological impairments (such as Parkinson’s disease, brain tumours, infections, poisoning or hypoxia), two of the principal causes of ABI include traumatic brain injury (TBI) and cerebrovascular accident (CVA). In a TBI, the damage to a person’s brain can result from the direct trauma or its consequences: hypoxia, diffuse axonal injury, hypotension, intracranial haemorrhage, and raised intracranial pressure. A CVA, often referred to as a stroke,
may result from ischaemic (occlusion of a blood vessel) or haemorrhagic (rupture of a blood vessel) causes (Turner-Stokes, Nair, Sedki, Disler, & Wade, 2005).

Within the TBI population, patients are typically divided into the broad categories of mild, moderate, and severe injury based on clinical indices of injury severity at presentation. The 15-point GCS (Teasdale & Jennett, 1974) is the most commonly used neurologic injury severity scale for adults, because of its high inter-observer reliability and generally good prognostic capabilities (Narayan et al., 2002). Patients with severe TBI are defined typically as having a GCS of 8 or less within the initial 48 hours following their injuring event (Saatman et al., 2008).

The term ‘complex ABI’ within this research references the heterogeneous nature of impairments, cognitive difficulties and functional limitations experienced by this population. The term also alludes to the dynamic set of personal and environmental factors that interact to determine the consequences of an ABI for the individual.

*Life goals*

Life goals are desired states, based on an idealised self-image, which people strive either to achieve, or seek to avoid, by means of cognitive and behavioural strategies. A focus on the attainment of life goals within rehabilitation services is thought to influence a person’s motivation to participate in their rehabilitation programme, and to impact on their subjective wellbeing. While the term *life goal* is used widely in psychological literature, it is only since the late 1990’s that it has been directly referred to, and researched, within the field of neurological rehabilitation.

1.5 **Thesis structure**

This thesis seeks to outline the processes that were used within this research, and to present the results that emerged. A review of the existing literature surrounding life goals (including their relevance to rehabilitation of people with ABI) is covered in chapter two. The clinical implications of the literature are also outlined briefly, along with theoretical models that inform the implementation of life goal planning in a clinical setting. The third chapter provides an overview of the methodological
framework, and methods utilised, within the current investigation. Theoretical perspectives that inform the methods used are also reviewed. The results from the current research are collated in chapter four, with three emerging supraordinate themes being described in detail. Finally the discussion chapter reviews the current results in light of the existing published literature, and makes recommendations for clinical practice and future research.
2 Literature review

2.1 Overview

There is a growing body of literature around what life goals are important, the attainability of life goals, and the effect of life goal achievement on subjective wellbeing for people with neurological disability. However, there is limited evidence around the utility of life goal planning in a clinical environment. This is especially evident in the ABI population where complex impairments, including cognitive changes, impact on the ability to effectively set, evaluate and achieve goals. This chapter outlines the current literature around the use of life goal planning in rehabilitation and seeks to set it within a context of wider rehabilitation service provision for people with ABI.

2.2 ABI epidemiology

ABI is one of the most common causes of disability and death in adults (Langlois, Rutland-Brown, & Wald, 2006; Strong, Mathers, & Bonita, 2007). ABI is an injury to the brain that results in cognitive impairments (E. Whyte, Skidmore, Aizenstein, Ricker, & Butters, 2011), changes to physical functioning (Whitnall, McMillan, Murray, & Teasdale, 2006) and emotional disturbances (Ponsford, Cameron, Fitzgerald, Grant, & Mikocka-Walus, 2011). It is a life event that can limit one’s activities, and impact on a person’s ability to participate in societal and occupational roles (Whitnall et al., 2006).

It is projected that TBI will become the third largest cause of global disease burden by 2020 (Traumatic brain injury: time to end the silence, 2010). Irrespective of age, 70–90% of TBI’s are mild with 5–20% being moderate and severe (Feigin, Barker-Collo, Krishnamurthi, Theadom, & Starkey, 2010). In New Zealand, Feigin et al. (2013) found the incidence of TBI to be 790 cases per 100 000 people. Extrapolation from this data to the world population suggests that every year 54-60 million people will experience a TBI, of whom 2.2-3.6 million will sustain a moderate to severe TBI (Feigin et al., 2013). These worldwide estimates are significantly higher than previous estimates, but are still likely to be conservative given that the incidence of TBI is
thought to be greater in low to moderate income countries than in those countries with high incomes. Males are at approximately twice the risk of TBI compared to females. There are also ethnic inequalities in TBI incidence and outcomes, with ethnic minority groups having greater TBI risk and higher post-TBI mortality (Feigin et al., 2010).

The World Health Organisation (WHO) reported that in 2004 the global incidence of a first ever stroke was 9 million per year (WHO, 2008). Moreover, stroke is a common cause of disability, with estimates that it will be the fourth most common cause of disability in western countries by 2030 (Donnan, Fisher, Macleod, & Davis, 2008). A range of findings for gender differences in the epidemiology, outcomes and treatment of stroke are reported. Men have higher age-specific stroke rates than women, and men are more likely to have their first-ever stroke at a younger age (Feigin et al., 2010). However, while age specific stroke rates are higher in men, women suffer more strokes in total and have worse outcomes because they live longer (Reeves et al., 2008). Ethnic disparities in prevalence and incidence of stroke, as well as related disability and mortality have been reported (Feigin et al., 2010). In New Zealand, Maori and Pacific populations have higher rates of stroke than Europeans and are likely to experience stroke at a younger age (Feigin et al., 2010; McNaughton et al., 2011).

2.3 Impact of an acquired brain injury

ABI frequently results in a sudden and fundamental interruption to a former way of life, leading to a time of transition (Doering, Conrad, Rief, & Exner, 2011; Ellis-Hill, Payne, & Ward, 2000). An ABI is known to disrupt and block life plans, threaten self-identity, and lead to a changed self-concept (Cantor et al., 2005; Ellis-Hill et al., 2000; Levack, Kayes, & Fadyl, 2010). This in turn can impact on a person’s quality of life and subjective wellbeing (Doering et al., 2011; Kuenemund et al., 2013).

However, impairments of body structure and function resulting from ABI do not correlate directly with subjective wellbeing and quality of life (Doering et al., 2011). The impact of an ABI is also influenced by, and mediated through, personal and environmental factors. There is increasing recognition of subjectively mediated responses to the impact of an ABI on one’s life and on one’s reactions to the event.
Gracey, Evans and Malley (2009) stated that a “complex and dynamic set of biological, psychological and social factors interact to determine the consequences of ABI” (p. 867). Ellis-Hill et al. (2008) have suggested that there has been a limited appreciation of the social and psychological processes that underpin rehabilitation. This has negatively impacted on the rehabilitation professional’s understanding of the ways people experience identity change following an acquired disability. Therefore a biopsychosocial approach (Engel, 1980) to rehabilitation services has been advocated (Gracey et al., 2009) and has become mainstream in some circles. This model posits that biological, psychological and social processes are integrally and interactively involved in a person’s health. The model highlights the importance of subjectively experienced consequences of illness or injury, individual resources, personal factors, environmental factors, and cognitive and behavioural reactions (Gracey et al., 2009).

2.4 Goal setting: a key rehabilitation approach

The identification of goals has been suggested to be a core component of rehabilitation (Playford et al., 2000). Goals that are personally relevant are the basis for a person-centred approach to rehabilitation service provision (Cott, 2004; Rosewilliam, Roskell, & Pandyan, 2011) and are thought to encourage patient engagement and help achieve better outcomes (Siegert & Taylor, 2004).

The primary premise of goal setting theory relates to the understanding that an outcome is positively influenced by the explicit setting of goals. Directing and refocusing attention, effort and motivation are therefore important factors when considering goal achievement. In the psychological research literature, striving for personal goals assigns meaning, structure and direction to an individual’s life. Discrepancies between aspired and actual states of being are a common experience after ABI (Gracey et al., 2009) and may negatively impact on the outcome of rehabilitation. The discrepancies may involve changed self-concepts, and goals that can no longer be achieved due to functional limitations.

There is a significant body of literature around concrete goal identification – the setting of specific and difficult individual goals to achieve performance gains. Bandura’s social cognitive theory (Bandura, 1977) and Locke and Latham’s goal
setting theory (Locke & Latham, 2002) provide two models for goal attainment that support the utility of specific goal setting. However, both of these models are more related to targets or short-term goals. They may have limited relevance to people’s life roles, and do not account for motivational influences in relation to higher representations of self. There is a need to explore the broader purposes for goal setting and to consider more over-arching, higher order values (Playford, Siegert, Levack, & Freeman, 2009; Rosewilliam et al., 2011). “It is increasingly recognised that understanding personal meanings and identity are vital if we are to work with people in a participatory way” (Siegert, McPherson, & Taylor, 2004, p. 1175). This has led to the exploration of the use of life goals within rehabilitation programmes for people following an ABI.

2.5 Life goals: definition, context and scope

Life goals are desired states that people seek to obtain, maintain or avoid, and they orient a person’s life course (Sivaraman Nair, 2003). Life goals are derived from core aspects of self, and relate to a system of beliefs and values within a hierarchical structure (Brands, Wade, Stapert, & van Heugten, 2012). The personal goals that a person strives for are determined by high-level abstract motivations, and an idealised self-image as shown in Table 2.1 (Sivaraman Nair, 2003).

Table 2.1: Hierarchy of goals

<table>
<thead>
<tr>
<th>Level</th>
<th>Goal</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Idealised self-image</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Abstract motivations</td>
<td>Power, fame, fortune</td>
</tr>
<tr>
<td>3</td>
<td>Personal goals</td>
<td>Career, family, relationships</td>
</tr>
<tr>
<td>4</td>
<td>Contextual goals</td>
<td>Striving for better grades at school</td>
</tr>
<tr>
<td>5</td>
<td>Immediate actions</td>
<td>Specific activities like reading, writing, playing</td>
</tr>
</tbody>
</table>

(Sivaraman Nair, 2003)

The pursuit of life goals can be interrupted by the experience of disability (Sivaraman Nair, 2003). Sivaraman Nair (2003) has argued that there should be an explicit link between treatment goals and life goals since, “motivation depends, to a large extent, on
concurrency between a patient’s life goals and the goals set by the rehabilitation team” (p. 197).

2.6 Search strategy

The aim of this narrative review was to identify and synthesise literature relating to the application of life goal planning in rehabilitation for ABI. A search for relevant articles was conducted in four electronic databases: MEDLINE, EMBASE, PsychINFO, and CINAHL. The search was limited to articles published in peer-reviewed journals, in English, between 1993 and June 2013. Searches were conducted by combining two groups of search terms (text words and subject headings) related to a) the study population (people with ABI) and b) the therapy topic (i.e. life goals). Search terms within each of these two groups were combined with the Boolean term ‘OR’ (to include any instance of a study where one or more terms applied). The results from these two searches were then combined with the Boolean term ‘AND’ (to included only studies which included terms related both ‘people with ABI’ and ‘life goals’). Table 2.2 provides a list of the keywords used for each of these two groups of search terms.

Table 2.2: Search terms

<table>
<thead>
<tr>
<th>Search term group</th>
<th>Search terms used</th>
</tr>
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<tbody>
<tr>
<td>People with ABI</td>
<td>Disability, acquired brain injury, stroke, cerebrovascular accident*, cerebrovascular disorder*, traumatic brain injury, brain injury, neurological injury</td>
</tr>
<tr>
<td>Life goals</td>
<td>Life goal*, life goal planning, life aim*, overarching goal*, idealized self, rehabilitation, experience* or lived experience*</td>
</tr>
</tbody>
</table>

After checking for duplicates across the databases 57 articles were found. Following a review of the abstracts 37 articles were selected for inclusion based on their applicability to the research question. Papers were included in this review if they reported on or examined some aspect of the theory or application of life goals to rehabilitation after ABI (see Figure 2.1). Both review articles and original research reports were included. Inclusion of studies was not limited by the methodologies used. The most seminal works related to this area (n=8) are outlined in Table 2.3. Publications were considered to be seminal if they provided a major contribution to the...
literature in terms of concept development, or if they explored the importance or use of life goals within the ABI population in a rehabilitation setting.

Figure 2.1: Process for inclusion of studies in the literature review
Table 2.3: Summary of key articles relating to life goals

<table>
<thead>
<tr>
<th>Author by year of publication</th>
<th>Focus of study / paper</th>
<th>Methods</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality appraisal and considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>McGrath and Adams (1999)</td>
<td>Examined the use of Carver and Scheier’s Self-Regulation Model (1990) in relation to goal setting in rehabilitation. Explored whether person-centred goal planning benefited patients in terms of reducing anxiety and distress.</td>
<td>Observational data and RLGQ&lt;sup&gt;1&lt;/sup&gt; Two parts: (1) descriptive account of the types of affective reactions that commonly occur after an ABI, and comment on these in relation to Carver and Scheier’s model; (2) examines the relationship between progress in goal-planning and the levels of emotional distress experienced by participants.</td>
<td>82 people with ABI 17 – 70 years</td>
<td>Progress in achieving rehabilitation goals was associated with reduced levels of psychological distress. Results provide some preliminary support for the use of goal planning (implicitly and/or explicitly informed by life goals) as a means of reducing anxiety and depression in rehabilitation.</td>
<td>Retrospective review of data collected in a clinical setting. Significant methodological issues. Person-centred goal planning was the term used although the RLGQ was used as a principal tool.</td>
</tr>
<tr>
<td>Sivaraman Nair (2003)</td>
<td>Conceptual framework around the development of life goals within the literature from 1970’s – 2003.</td>
<td>Review article (n=39) Examination of life goals and their influence on the rehabilitation process: nature of goals; effect of life goals on health; impact of illness on life goals; tools for the assessment of life goals; and role of life goals in rehabilitation.</td>
<td>NA</td>
<td>Including subjects’ life goals in a management programme results in better outcomes in various physical and psychiatric disorders. There is no data of the efficacy of life-goal orientated rehabilitation programmes.</td>
<td>Not a systematic literature review however 39 papers reviewed. Lack of clarity around the search strategy. Only includes literature until 2003.</td>
</tr>
<tr>
<td>Sivaraman Nair &amp; Wade</td>
<td>Study aimed to identify life goals in a sample of people with neurological disorders, and to measure the relationship between life goals and</td>
<td>Cross-sectional descriptive study Survey based utilising</td>
<td>n=93 (aged 27-65 years) with static or progressive neurological disorders</td>
<td>Goals change through the life span, and over time, particularly in people with progressive disorders. Coping with disability occurs partially through reducing significance to</td>
<td>Only modest statistical significance with correlations. 10% of people excluded due to severe</td>
</tr>
</tbody>
</table>

<sup>1</sup> Rivermead Life Goals Questionnaire
<table>
<thead>
<tr>
<th>Author by year of publication</th>
<th>Focus of study / paper</th>
<th>Methods</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality appraisal and considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>(2003a)</td>
<td>disabilities.</td>
<td>RLGQ</td>
<td></td>
<td>unattainable goals and in developing new ones. People with both static and progressive neurological disabilities attach great significance to relationships with their partner or other family members, personal care and residential/domestic arrangements. Person-identified life goals are much broader than the physical needs often focused on in the clinical rehabilitation setting.</td>
<td>communication or cognitive problems. Small sample size. Single centre study.</td>
</tr>
<tr>
<td>Sivaraman Nair and Wade (2003b)</td>
<td>To investigate the effect of long term disability on changes in life goals among people with static or progressive neurological disability.</td>
<td>Retrospective study - using the Barthel ADL² Index and RLGQ for four consecutive years.</td>
<td>n=32 people with progressive disability and n = 24 people with static disability</td>
<td>The number of extremely important life goals for people with progressive disability reduced over time. There was also a tendency to downgrade the significance of goals (particularly work, relationship and leisure goals) over time.</td>
<td>Some methodological issues as different professionals collected the data each year and there is no published data around the inter-rater reliability of the RLGQ. Also a limited range of disability included in the sample and a relatively small sample size. A longitudinal prospective study including participants with a wider range of disabilities may add to the generalisability of the findings.</td>
</tr>
<tr>
<td>McNamara, Durso &amp; Harris (2006)</td>
<td>Tests the hypothesis that people with Parkinson’s disease would be impaired or derailed in their ability to achieve their life goals (compared to age matched controls) since they have</td>
<td>Cross-sectional descriptive study with age matched controls RLGQ used</td>
<td>n=22 males with Parkinson’s disease n=22 (male and female) controls.</td>
<td>Less life goals were on track in people with Parkinsons Disease (relative to controls) and subjective importance ratings were related to mood but not to cognitive functioning.</td>
<td>As a pilot exploration there are methodological limitations, particularly around the number of men relative to women in the convenience sample. RLGQ has not been validated in terms of the on track component added in this column.</td>
</tr>
</tbody>
</table>

² Activities of Daily Living
<table>
<thead>
<tr>
<th>Author by year of publication</th>
<th>Focus of study / paper</th>
<th>Methods</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality appraisal and considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conrad, Doering, Rief &amp; Exner (2010)</td>
<td>To identify subjective importance and attainability, of life goals. To identify the most relevant life goals for promoting wellbeing.</td>
<td>Cross-sectional descriptive study, using questionnaires (GOALS(^3) and SWB(^4)) Normative data from a representative sample of n=2396 healthy controls</td>
<td>59 people with ABI (mean ABI duration of 2.4 months)</td>
<td>In this sample the most important life goals were intimacy, achievement and altruism. Intimacy was also considered to be the most attainable and patients perceived themselves to be most successful in this domain. The most powerful predictors of subjective wellbeing were success in the achievement domain and the discrepancy between importance and success in the intimacy domain. It is not only the importance, but primarily the experienced progress towards life goals, that influences subjective wellbeing.</td>
<td>Sample group relatively acute (2.4 months). Small sample size therefore only a limited number of predictor included in multiple regression models. SWB is a very broad category of phenomenon and measures used are open to critique. Regression analyses used are suggestive rather than definitive. A priori assumptions and predictions of the study are based on basic psychological research and have not been verified in longitudinal studies in ABI population.</td>
</tr>
<tr>
<td>Doering, Conrad</td>
<td>To investigate life goal discrepancies and their</td>
<td>Cross-sectional descriptive study using GOALS</td>
<td>n = 130 inpatients and n = 42 outpatients from</td>
<td>Inpatients and outpatients both reported greater discrepancies</td>
<td>SWB operationalised as a composite</td>
</tr>
</tbody>
</table>

\(^3\) Life Goals Questionnaire  
\(^4\) Subjective wellbeing
<table>
<thead>
<tr>
<th>Author by year of publication</th>
<th>Focus of study / paper</th>
<th>Methods</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Quality appraisal and considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rief &amp; Exner (2011)</strong></td>
<td>influence on SWB in different stages of rehabilitation and recovery. Aimed to look at goal adjustment issues in the presence of chronic functional impairment.</td>
<td>questionnaire</td>
<td>four different rehabilitation settings (59 of inpatient sample were the n=59 included in Conrad et al 2010 study) Normative sample of healthy controls</td>
<td>between importance and success of life goals than normative controls. Goal discrepancy predicted SWB in inpatient sample despite functional limitation - especially in domains of intimacy and achievement. In outpatient sample there was a relationship between goal discrepancy and functional limitation in predicting SWB. Inpatients with TBI reported greater SWB compared to patients after a stroke, despite controlling for differences in functional limitation.</td>
<td>score – open to critique. Study design unable to clarify underlying cognitive processes that could account for goal discrepancies, particularly over time. Cross-sectional design therefore cannot establish causality of hypothesised relationships. Small outpatient sample – stability of associations? Risk of single source bias in data acquisition – inflated inter-relations?</td>
</tr>
<tr>
<td><strong>Kuenemund, Zwick, Doering, Conrad, Rief, &amp; Exner (2013)</strong></td>
<td>Aimed to investigate changes in the importance and the attainability of communion and agency life goals, and their impact on SWB.</td>
<td>Prospective longitudinal study using GOALS questionnaire</td>
<td>N = 42 people with ABI (mean age of 52 years) Baseline = 2 months following ABI Reassessed = 19 months following discharge</td>
<td>Life goal importance stable over time Attainability of communal life goals significantly predicted SWB (agency goals did not predict SWB) Long term deterioration in life goal attainability.</td>
<td>Less than 50% of original sample available for follow-up. Small sample size – predominately stroke (90%) with only 2.4% TBI. Mean age of 52 years – not able to generalise to younger ABI population (although very similar to the age of the participants in my sample group). Significant positive associations between communal and agency goal construction i.e., they did not appear to be independent of each other.</td>
</tr>
</tbody>
</table>
2.7 Personal and contextual factors

In the general population age, gender, personality, society and environment are factors that have been shown to influence life goals (Sivaraman Nair, 2003). Life goals have been shown to change throughout the lifespan (Nurmi, Pulliainen, & Salmela-Aro, 1992). During early adulthood, life goals tend to be orientated towards education, occupation, the selection of a partner, starting a family and finding a congenial social group. Goals at middle age tend to be related to maintaining a satisfactory occupation, meeting the demands of parenthood, nurturing relationships and managing a household. Late life goals tend to be related to health, spirituality and adjusting to retirement, reduction of income and bereavement. The work of Carstensen and colleagues (Carstensen, Fung, & Charles, 2003) also suggests that socio-emotional life goals become more important in the second half of life due to the increasing awareness of the limited life span.

Gender also appears to influence the choice of life goals with women giving higher importance ratings to family, domestic and social goals and men tending to attribute higher importance ratings to economic and occupation goals (Sivaraman Nair, 2003). People who are in paid employment tend to place more importance on work than people who are not in paid employment (Sivaraman Nair & Wade, 2003a). Higher importance ratings on financial status have been shown to be associated with anxiety (Sivaraman Nair, 2003). Life goals around striving for financial success, attractiveness and fame have been consistently negatively correlated with different measures of wellbeing, while goals associated with affiliation, community, and connection with others have been found to be positively related to wellbeing (Conrad, Doering, Rief, & Exner, 2010).

Personality has also been found to play an important role in the choice of life goals. People with Type A personalities are often more dissatisfied with goal attainment (Sivaraman Nair, 2003) while extroversion and narcissism are positively correlated to agentic (achievement, hedonism and power) goals and negatively correlated with communal (affiliation, altruism and intimacy) goals (Kuenemund et al., 2013).
Affect appears to impact on both the choice of life goals and the intensity of goal-striving behaviour (Emmons, Colby, & Kaiser, 1998). Depressed patients rate fewer goals as being of extreme importance. Higher scores of depression have also been associated with lower significance given to personal care and social contacts (Sivaraman Nair & Wade, 2003b). A recent study in people with arthritis (Arends, Bode, Taal, & Van de Laar, 2013) showed that a high tendency to keep a focus on goal attainment was related to fewer depressive symptoms, and also to more purpose in life, a positive affect, and satisfaction with work participation.

These personal and contextual factors therefore raise questions about how culturally and socially bound, or determined, life goals are. These considerations should be taken into account when researching the role of subjectively reported life goal importance and attainment characteristics within the current investigation.

### 2.8 Assessment and measurement

Life goals are accessible to conscious awareness and can be measured (Emmons et al., 1998). This section outlines how life goals are assessed and measured within the literature, and in the clinical environment. When reviewing the assessment tools it is important to consider which level of the life goal hierarchy is the focus of measurement. Is the assessment tool attempting to gain information from people about concrete goals, or is it seeking to explore more abstract representations of a person’s self-concept? The premise within the published literature is that life goal assessment at the level of abstract motivations may be difficult for people with cognitive impairments (Sivaraman Nair, 2003). The most common assessments used within the brain injury literature include the Rivermead Life Goals Questionnaire (RLGQ) and the Life Goals Questionnaire (GOALS). Table 2.4 shows the range of life goal categories covered in these key assessment tools, and highlights at what level of the hierarchy the questions are aimed at. Full copies of the RLGQ and GOALS questionnaire can be found in Appendices 1 and 2.
Table 2.4: Life goal assessment tools

<table>
<thead>
<tr>
<th>Questionnaire</th>
<th>Goal Categories</th>
<th>Hierarchy level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rivermead Life Goals Questionnaire (RLGQ)</td>
<td>• Residential / domestic arrangements</td>
<td>The life goal areas assessed are based at the level of personal goals within the hierarchy of life goals.</td>
</tr>
<tr>
<td></td>
<td>• Personal care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Leisure / hobbies</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Work – paid / unpaid</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Relationship with partner</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Family life</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Neighbours / friends / acquaintances</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Religion / life philosophy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Financial status</td>
<td></td>
</tr>
<tr>
<td>Life Goals Questionnaire (GOALS)</td>
<td>• Intimacy - to have a close relationship</td>
<td>The life goal areas assessed are based at the level of abstract motivations within the hierarchy of life goals.</td>
</tr>
<tr>
<td></td>
<td>• Affiliation - to spend a lot of time with other people</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Altruism - to act unselfishly</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Power - to have a high social status</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Achievement - to improve my skills continuously</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Variation (hedonism) - to live an exciting life</td>
<td></td>
</tr>
</tbody>
</table>

**Rivermead Life Goals Questionnaire (RLGQ):**

The RLGQ (Appendix 1) is a structured self-report inventory developed at the Rivermead Rehabilitation Centre, Oxford (Sivaraman Nair, 2003). It is a nine-item questionnaire where subjects are asked to rate the relative importance of nine life goals from 0 (no significance) to 3 (extreme significance). As can be seen in Table 2.4 the life goals areas assessed are based at the level of personal goals within the hierarchy of life goals. The stated reason for the assessment at this level in the hierarchy is the perception that scales aimed at the level of abstract reasoning may not be practical in people with brain injury with cognitive deficits (Sivaraman Nair, 2003).

A preliminary study (McGrath & Adams, 1999) showed good test-retest reliability for the questionnaire. Sivaraman Nair and Wade (2003a) used the RLGQ for two studies looking at life goals in people with neurological disability, and given that there was no
significant change in overall ratings over the four-year period, they reported that this was suggestive of validity and reliability. Nevertheless, no formal psychometric analyses have been published related to this tool.

The RLGQ does not tell us whether or not the patients feel that they are satisfactorily attaining their life goals – whether their attempts to reach their life goals are on track. Also, all studies using RLGQ came up with very similar patterns of importance ratings. However, there is no data of the use of the RLGQ in the general population and therefore one cannot make comparisons between the importance ratings seen in these studies, and the importance ratings within the general population.

**Life goals questionnaire (GOALS):**

The GOALS questionnaire was developed by Pöhlmann (2001) and is explicitly aimed at higher level representations of self. Life goals are regarded as higher order phenomena since “they embody one’s perceptual orientation of ones’ life on a relatively abstract level” (Conrad et al., 2010, p. 434). The questionnaire was initially developed in German; however, I obtained a translated English version from Pöhlmann for the purpose of this review (Appendix 2).

The GOALS questionnaire includes 24 items that evaluate life goals corresponding to six categories. Items are evaluated using a 5-point rating scale (1=not; 5=very). Three goal dimensions are evaluated for each goal, i.e., importance, attainability, and success. Domain specific discrepancy scores are calculated by subtracting a goal’s success rating from the respective importance rating. Within this measure the concepts of ‘achievement’, ‘hedonism’, and ‘power’ are considered to reflect *agentic-oriented* strivings, whereas ‘affiliation’, ‘altruism’, and ‘intimacy’ are considered to cover *communion-oriented* strivings. Kuenemund et al. (2013) used these individual subscale groupings to obtain an overall score for each of the *communion* and *agency* variables within their research.

Conrad et al. (2010) have argued that the GOALS questionnaire is a more theoretically driven instrument than the RLQG. The presence of recently collected normative data has also allowed researchers to compare their specific sample with a normative control group. Good to very good internal validity of items and scales was seen in the
normative sample, however, there is no information regarding its psychometric properties in neurological populations (as cited in Doering et al., 2011). The English translation of this assessment has not been tested for its psychometric properties. Conrad et al. (2010) have also reported that accordance has been found between life goals assessed as part of an individual interview and those captured via the GOALS questionnaire.

**Assessment in clinical practice:**

Most recent literature around life goal assessment in people with neurological impairments in clinical environments recommend an iterative, idiographical way of obtaining information about life goals (Conrad et al., 2010). “Assessment of life goals in people with neurological disorders is complicated by problems in communication, cognition, emotion and motor skills” (Sivaraman Nair, 2003, pp. 196-197). This can make it difficult to obtain information about life goals. Emotional upset, a lack of insight and the loss of ability to make judgments and to undertake abstract thinking are common. It is thought that these factors can interrupt the formulation, assessment and communication around the intention and success of life goals. However, a change to more idiographic approaches was not only noted in the literature relating to those with neurological (including cognitive) impairments. This move to idiographic assessment approaches was also noted in the literature around people with visual loss - where there was a change in study methods over the arc of the research programme due to researchers finding that these approaches also worked better when assessing for goals in the research context (Boerner & Camarolli, 2005; Popivker, Wang, & Boerner, 2010).

One issue that needs to be considered in the assessment of life goals is the impact of social desirability on the responses of participants. Conrad et al. (2010) make this comment particularly around the responses relating to altruism. A further important issue is the objectively perceived reliability of the individual’s responses given the varying levels of self-awareness likely within participants in a population of people with neurological impairments, and particularly in those with frontal lobe damage. This is explored further in the discussion chapter.
2.9 Life goals: influence of illness and disability

Neurological diseases and consequent disabilities may interrupt the pursuit of life goals (McGrath & Adams, 1999; Sivaraman Nair & Wade, 2003a, 2003b). Cognitive changes can negatively affect planning, impulse control and resistance to goal interference. This in turn impacts on a person’s ability to effectively pursue life goals (McGrath & Adams, 1999). Impairments and disability can directly impact on a person’s future aspirations by both removing opportunities, and by creating new possibilities. Doering et al. (2011) also demonstrated that the discrepancies related to goal importance and success across all life goal domains, are larger for patients after ABI than in a normative control sample.

Life goals appear to be relatively constant in people who have a stable level of disability. However, in chronic progressive disorders the rate of approach to desired goals is particularly unpredictable, slowed, or interrupted. It has been shown that in long-term acquired disability this can result in emotional distress (Sivaraman Nair & Wade, 2003a, 2003b). Nair and Wade (2003a) undertook a study that retrospectively examined longitudinal change of life goals in a group of people with progressive and static neurological disability. Patients with static diseases reported relative stability of life goals over one year. However, patients with progressive diseases reported a diminishing importance of various life goals, and a decrease in the number of life goals considered extremely important. People with progressive disabilities tended to downgrade significance attached to goals related to partner, work and leisure. However, it should be noted that in this sample, people with progressive disabilities had less severe impairments and had been disabled for a shorter period of time compared with those with static diseases. By year four, their disabilities had progressed to a level similar to that of the static group. The reducing significance being given to partner, work and leisure goals over this time may be due to these goal areas being viewed as less achievable by the participants as their disabilities progressed. This could account for the downgrade in significance. Nevertheless the relative stability of a neurological disability does appear to impact on a person’s life goal identification and achievement.
The effective use of cognitive and behavioural strategies is required for a person to achieve their goals (Hart & Evans, 2006; Sivaraman Nair, 2003). ABI deficits can have adverse effects on goal setting, goal directed behaviours and on the effective evaluation of goal achievement. Productive goal directed behaviour requires a level of executive functioning often impaired following a brain injury. These executive functions include planning, self-monitoring, behavioural control and memory (Hart & Evans, 2006). Lengfelder and Gollwitzer (2001) have demonstrated difficulties in the deliberation of new goals and the formation of goal intentions, in patients with frontal brain lesions. Fischer, Gauggel and Trexler (2004) have also shown that impaired awareness of deficits predicts poor rehabilitation outcomes, along with a reduced ability to set realistic rehabilitation goals. However, in a cross-sectional descriptive study including 22 men with Parkinson’s disease (and known cognitive decline), McNamara, Durso and Harris (2006) did not find a significant correlation between importance ratings of life goals and executive functioning. They did however, find a positive correlation between mean life goal importance ratings and mood function scores – that is, people with low scores on mood tests were more likely to rate their goals as being off track.

Coping with disability appears to occur partially through reducing significance to unattainable goals and partially through the development of new goals. For example, Sivaraman Nair and Wade (2003b) found that people who were more dependent on others for their physical needs reduced the significance they attached to goals related to personal cares. Nevertheless there is a need for further prospective research to clarify the adjustment processes and longitudinal changes in life goals over time in people with neurological disability.

2.10 Relevance of life goals in rehabilitation

Within the existing body of literature, the reasons that life goals are thought to be important in the provision of rehabilitation services relate to two aspects: motivation and wellbeing.
2.10.1 Motivation

“Motivation is a dynamic variable that results from the interplay among the goals that an individual aspires to, their rate of progress towards those goals, and their skill at regulating their own thoughts, feelings and emotions in the pursuit of such goals” (Siegert & Taylor, 2004, p. 1181). This definition explicitly pushes back against the view of motivation as being a personal factor, or trait, which is immune to change. Rather motivation is seen as incorporating both relational (concerning both the professional and the client) and social (contextual) factors (Maclean & Pound, 2000; Maclean, Pound, Wolfe, & Rudd, 2002). In most contemporary psychological theories of motivation, goals and the concept of motivation are inextricably linked. Therefore we cannot understand goal directed behaviour without understanding motivation, and vice versa (Siegert & Taylor, 2004).

Life goals are thought to influence a person’s motivation to participate in rehabilitation. Motivation depends, in part, on the concurrence between a patient’s life goals and treatment goals (Siegert & Taylor, 2004; Wade, 1998) since the setting of goals at any level is determined by the goal of the next level up in the hierarchy (refer to Table 2.1). It is thought that striving for personal goals assigns meaning, structure and direction to a person’s life (Wong, 2012). However, there are limited studies that empirically test if rehabilitation programmes that utilise life goal planning have a positive effect on levels of motivation. The limited body of research related to the influence of goal planning on motivation may be due, in part, to difficulties in operationalising motivation in the research of clinical neurological rehabilitation programmes.

**Control-Process Model of Self-Regulation:**

Within the rehabilitation literature, aspects of motivation relating to goal setting are often informed by the Control-Process Model of Self-Regulation (Carver & Scheier, 1990). Siegert, McPherson and Taylor (2004) have argued that self-regulation theory, and particularly the Control Process Model of Self-Regulation, may provide a useful model for goal setting practice, theory building and research. Carver and Scheier (1990) posited that human life is a continual process of establishing goals and intentions and adjusting current patterns of behaviour so as to more closely match
these goals. In this model a goal is a reference point or target towards which a person intends to move. They suggested that an action is undertaken to minimise the discrepancy between the current state and some behavioural reference. As a negative feedback cybernetic system (Figure 2.1), it suggests that feedback-based processes are used to self-regulate actions in order to decrease the discrepancies between a desired end state (or goal) and the individuals current perceptions of the situation (Carver & Scheier, 1990). If the comparison indicates discrepancies between the intended and actual behaviour, people adjust their actions (output function) to move closer to the reference value (goal).

*Schematic depiction of a feedback loop.* In such a loop a sense value (input function) is compared to a reference value or standard, and adjustments are made (if necessary) in an output function (behaviour) to shift the sense value in the direction of the standard. The final element in this figure – disturbance – conveys the sense that factors external to the system can also influence the nature of the current state. (Carver & Scheier, 2000)

**Figure 2.2: Carver and Scheier’s feedback loop**

*Distance* from the goal is less important than the *rate* at which the goal is approached in that “affect pertains to one’s desires and whether they are being met” (Carver & Scheier, 2011, p. 6). Carver and Scheier (1990) suggested that positive or negative feelings are a response to the rate at which the discrepancies are being reduced in the
action system over time. The amount of discrepancy is not thought to be an important mediator of affect. “What is important...is not merely whether discrepancies are being reduced at the level of the action loop, but how rapidly they are being reduced” (Carver & Scheier, 1990, p. 22). Their argument was that positive feelings occur when you are doing better at something than you need to, and negative feelings arise when you are doing worse than you need to. The feelings also have an influence over subsequent behaviour, with negative efforts leading to efforts to catch up, and positive feelings leading to coasting behaviour (Carver & Scheier, 2000).

An important principle within the model, which relates closely to the concept of life goals in rehabilitation (Table 2.1), is the notion that behaviour and goals are organised hierarchically (Figure 2.2).

Figure 2.3: Hierarchy of goals (or feedback loops)

Terms on the left side of figure identify the levels of control. Lines indicate the contribution of lower level goals to specific higher-level goals. They can also be read in the opposite direction, indicating that a given higher-order goal specifies more concrete goals at the next lower level. The hierarchy depicted involves goals of ‘being’ particular ways, which are attained by ‘doing’ particular actions. (Rasmussen, Wrosch, Scheier, & Carver, 2006)
The general assumption is that the higher in this hierarchy a particular goal is, the more central to the overall sense of self or idealised self-image. “Commitment to goal attainment will depend to a large extent on how consistent the lower level goals are with the individual’s super-ordinate goals” (Siegert et al., 2004, p. 1180). The fulfilment of lower level goals leads to the realisation of higher level motivations (Sivaraman Nair, 2003) and it is thought that attention to life goals assists in structuring the treatment goals within a rehabilitation programme (Doering et al., 2011).

It has been argued that this model of self-regulation model is very compatible with a client-centred approach to rehabilitation “emphasising as it does self-control, self-awareness and self-management” (Siegert et al., 2004, p. 1182). However, while goal setting involves establishing specific reference points, or desired end states, one question not answered by the model is: where does the standard of comparison come from? Are these comparisons internally or externally driven and are they able to be adjusted in response to a sudden change in a person’s functional abilities?

The body of published research relating to the motivational implications of life goals does not include empirical data relating to perceived goal attainability and success criteria. Instead it focuses purely on the relative importance given to different life goal areas. In response to this gap, a second body of literature has developed exploring life goal attainability and success particularly with respect to the promotion of subjective wellbeing.

### 2.10.2 Wellbeing

A key aim of the body of literature investigating the relationships between life goals and subjective wellbeing is to explore whether adaptation to ABI changes in the attainment of life goals might offer a way to regain or maintain subjective wellbeing following an ABI (Kuenemund et al., 2013). Subjective wellbeing can be defined as a “broad category of phenomena that includes people’s emotional responses, domain satisfactions and global judgements of life satisfaction” (Diener, Suh, Lucas, & Smith, 1999, p. 277).
Subjective wellbeing includes affective as well as cognitive components and is closely linked to self-rated disability ratings. For example Whitnall et al. (2006) found clear evidence of an association between adverse self-ratings of emotional wellbeing, and moderate or severe disability in a representative cohort of people five to seven years following a TBI. They suggested that attention given to wellbeing after a TBI is warranted to reduce disability in the longer term.

Commitment to life goals and perceived progress towards life goals contributes to health and psychological wellbeing. This commitment also provides meaning and structure to peoples’ lives. Sivaraman Nair’s (2003) narrative review highlighted that a lack of commitment to life goals led to a sense of meaninglessness, increased stress and mood disorders. Confusion also occurs when the goal monitoring process is disrupted because of misinformation or cognitive problems (McGrath & Adams, 1999; Sivaraman Nair, 2003). Higher self-rated subjective wellbeing may also contribute to an ability to engage with the setting and achievement of life goals. Nair and Wade (2003a) reported, “several studies have shown that people with a high sense of wellbeing have better recognition of life goals, commitment to life goals, perception of progress towards life goals and sense of achievement of life goals” (p. 797).

There is an increasing body of evidence demonstrating that goal success and goal achievement contribute to wellbeing whereas goal importance does not. Conrad et al. (2010) found that it was primarily the experienced progress towards life goals, and not only goal importance, that influenced subjective wellbeing. Kuenemund et al. (2013), in a prospective longitudinal study of 42 adults with neurological disability (mean age = 52 years), also found that higher attainability of life goals was associated with a higher level of subjective wellbeing at follow-up.

The influence of avoidance goals versus approach goals on subjective wellbeing has also been reported (Elliot, Sheldon, & Church, 1997). Conrad et al. (2010) found that “persons who strive for avoidance goals rather than for approach goals more often experience anxiety feelings, dissatisfaction with life or physical symptoms and report less wellbeing experiences” (p. 432).
McGrath and Adams (1999) have empirically examined the Control-Process Model of Self-Regulation (Carver & Scheier, 1990) in a neurological rehabilitation setting to determine if goal planning had a therapeutic value in terms of emotion and wellbeing. They concluded that progress in achieving rehabilitation goals in 82 patients with an ABI was associated with reduced levels of psychological distress, including an anxiety reducing effect. The study has several limitations, including no control group and goal planning not being compared with any other intervention. However, it does provide preliminary support of the value of goal planning in supporting a persons’ sense of wellbeing while undergoing rehabilitation.

**Personal Goal Model of Subjective Wellbeing**

A key model in the life goal literature that relates to wellbeing is Brunstein’s (1993) Personal Goal Model of Subjective Wellbeing. The Personal Goal Model of Subjective Wellbeing concentrates on goal importance, attainability, success and motive congruence. In this model the term ‘motive congruence’ relates to the lack of discrepancy between an individual’s implicit or unconscious motives, and their explicit of conscious goals.

Three basic predictions are made. First, attainability moderates the relation between goal commitment and goal success. Second, goal success mediates the influence of goal commitment on subjective wellbeing. The third prediction concerns the moderating impact of motive congruence. Reproduced from Conrad, et al., (2010).

![Figure 2.4: The Personal Goal Model of Subjective Wellbeing](image)

The Personal Goal Model of Subjective Wellbeing links goals to subjective wellbeing by the means of specific goal characteristics. These characteristics include goal...
commitment, goal attainability, and progress in goal achievement. As shown in Figure 2.3, the model makes a number of predictions that are supported in longitudinal psychological literature (Brunstein, 1993).

The first two assumptions of the model were supported by findings of a recent study examining the life goal characteristics that contribute to a person’s subjective wellbeing as applied to people with neurological disorders (Conrad et al., 2010). In this study a sample of 59 inpatients with ABI demonstrated that the influence of goal importance on subjective wellbeing was mediated by perceived goal success. The most significant predictors of subjective wellbeing were success in the achievement domain, along with discrepancy scores of importance in intimacy related goals, and success in achieving them. This study supports the notion that it is not only the importance of life goals that influences subjective wellbeing – attainability and success also plays an important intermediate role (see Figure 2.3). “Only if patients feel success in striving for subjectively important life goals do their wellbeing perceptions increase” (Conrad et al., 2010, p. 438). However, it should be noted that predictions upon which this study are based have not been verified in longitudinal studies in the ABI population although they have been validated in basic psychological research. Additionally, the sample in this study had a mean duration of injury of 2.4 months thereby limiting generalisation of these results to people with longer-term disability.

In a related study, Doering et al., (2011) found that inpatients who experienced greater discrepancy between personally important goals and their individual success in attaining these goals (particularly in the intimacy and achievement related domains), reported less subjective wellbeing independent of functional limitations. Interestingly, in this sample, patients after TBI reported greater subjective wellbeing than patients suffering from stroke or other forms of ABI. Also, outpatients with a longer time since injury reported less subjective wellbeing. Doering et al. (2011) suggested that in later stages, when deficits prove to be chronic in nature, their impact on life satisfaction and subjective wellbeing may change. However, there were a number of limitations within the design of Doering et al.’s (2011) study, which means that we need to treat these findings with caution. Firstly, there was the possibility for selection bias in both the inpatient and outpatient sample groups. Secondly, the small outpatient sample (n=42) as compared to inpatient sample (n=130) questions the stability of the association’s
found. Thirdly, there is also the risk of single source bias in the data acquisition, which could inflate the interrelationships found. Finally the study uses a cross-sectional descriptive design, and therefore cannot establish causality of the hypothesised relationships.

Nevertheless, subjective wellbeing is an important rehabilitation outcome and it is feasible that life goal interventions could provide a promising intervention strategy (Conrad et al., 2010). Subjective wellbeing is of course a broad category of phenomena, including both affective as well as cognitive components. Operationalising this concept is difficult, particularly in those with severe memory loss or other cognitive impairments. Furthermore, the body of literature does not provide empirical data on the processes that lead to reduced attainability and success with life goals following an ABI. Additional research in this area is needed.

### 2.11 Life goals: what are important?

Within the published research the high importance attributed to various life goal domains has been investigated. Table 2.5 overviews the importance ratings of life goal domains as discussed in this section.

In 2003 Nair and Wade published two studies that focused on goal importance in a sample of people with neurological disability. They reported that people with static or progressive neurological disorders tended to most commonly rank the development of their relationships with partners and other family members, their personal cares, and their residential and domestic arrangements as being their most important life goals. The first study (Sivaraman Nair & Wade, 2003b) used a cross sectional descriptive design to identify the life goals of 93 people aged between 27 - 65 years with long-term neurological disabilities, correlating these with measures of disability. It is important to note that 10% of people were excluded from the sample due to severe communication and cognitive problems, thereby limiting generalisability of the study findings to people with very severe impairments. The second study (Sivaraman Nair & Wade, 2003a) used a retrospective design to investigate the effect of long term disability on changes in life goals among people with permanent or progressive neurological disability over a four-year period. Fifty-six people (aged 24-60 years)
with neurological disability (n=32 progressive; n=24 static) of a long-term duration (3-46 years) were included in the sample. In this study different professionals had collected the life goal data over the four-year period using the RLGQ that, importantly, has not been validated in terms of inter-rater reliability.

Despite these limitations it is clear for these studies that participants with disabilities tended to place high value on goals related to relationships with their partner and families. Sivaraman Nair and Wade (2003b) found that 67% (n=93) of participants with long term neurological disability rated relationships with family members or partners as extremely important regardless of age, duration and severity of disability, and presence of anxiety or depression. In Nair and Wade’s study (2003a) which investigated changes in life goals over time, participants (n=56) also rated their relationships with partner (63%) and family (67%) as being extremely important when averaged across the four-year period.

More recently published studies have also provided evidence supporting the primary importance given to relationship life goals. Conrad et al. (2010) found that the intimacy category in the GOALS questionnaire was rated the most important life goal area, and also the most attainable and most successfully achieved in their sample group. Kuenemund et al. (2013) found that communal life goals (‘affiliation’, ‘altruism’, and ‘intimacy’) were rated as significantly more important, more attainable and more successfully achieved than agentic goals (‘achievement’, ‘hedonism’, and ‘power’) at baseline and follow-up. Similarly, McNamara et al. (2006) showed that people with Parkinson’s disease evaluated themselves as more successful in relationship life goals compared with age-matched controls. The relative importance of relationships was also demonstrated in the work of McGrath and Adams (1999) and has not only been seen in the neurological population. Boerner and Cimarrolli (2005) also found goal disturbances, particularly in goals related to partner and family relationships, were significantly correlated with wellbeing indicators in their sample of people with visual loss.

Interestingly, Nair and Wade (2003a) found that in people with progressive disabilities, there was a significant reduction in grades given to the importance of a partner over four years and suggest that this could be due to stress in the relationships.
and especially on spouses over the longer term. Also, McNamara et al. (2006) found that although partner and family relationships were graded as most important, most patients with Parkinson’s disease did not cite these relationship goals as being off track. It should be noted however, that this study included a convenience sample of only males with Parkinson’s disease. In the review of the literature, Sivaraman Nair (2003) found that a “preoccupation with achievement related goals to the exclusion of relationship goals resulted in stress” (p. 525). He contended that rehabilitation services tend to focus on work and leisure goals over those related to family and relationships. This finding was also supported in follow-up cross-sectional descriptive study (Sivaraman Nair & Wade, 2003b).

An ability to manage one’s own personal care (including dressing, toileting and washing), and one’s residential and domestic arrangements (where a person lives and who they live with) was also rated as highly important in Nair and Wade’s studies. Sivaraman Nair and Wade (2003b) found that independent everyday functioning was rated as being extremely important by 63% of the participants, and residential arrangements were rated as extremely important by 62%. In this study the grades attributed to these goals were negatively associated with scores of independent mobility. People with higher scores on scales of independence in activities of daily living placed more importance on their ability to manage personal care, while people who were dependent in activities of daily living did not attach significance to this goal. Sivaraman Nair and Wade (2003) postulated that this might be due to participants downgrading the significance of this goal as they adapt to a loss of functional skills. In the second study, Nair and Wade (2003a) found that when averaged across the four years, 58% and 60% of their participants scored life goals related to personal care, and residential and domestic arrangement, domains as being extremely important.

Conrad et al. (2010) also found that after relationships, the domains of achievement and altruism were most often rated as extremely important, and were found to be significantly more important for the sample group than for the control group. Both Conrad et al. (2010) and Doering et al. (2011) included control group data in their research design, and both studies concluded that the participants who were rehabilitation patients did not differ from the healthy control group in terms of the way
they ranked the relative importance of various life goals as measured by the GOALs questionnaire.

In their prospective longitudinal study, Kuenemund et al. (2013) found that stated life goal importance remained stable over time for adults (n=42) with ABI. This finding was not expected and may suggest that reprioritisation of life goals had not automatically occurred in the two-year period since the ABI. One reason for this finding may be the mean age (52 years) of the participants, since younger patients may have previously had a stronger focus on agentic, future-related life goals and may have therefore shown a stronger shift in priority following an ABI.
Table 2.5: Overview of importance ratings of life goal domains in the literature

<table>
<thead>
<tr>
<th>Paper Authors</th>
<th>High importance</th>
<th>Intermediate importance</th>
<th>No or low importance</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sivaraman Nair &amp; Wade (2003a)</td>
<td>Relationships with partner/families Personal care Residential and domestic arrangements</td>
<td>Leisure Financial status Friends Social contacts</td>
<td>Religion/life philosophy Work</td>
<td>No difference in overall pattern over four years, and between progressive and static disability</td>
</tr>
<tr>
<td>McNamara, Durso &amp; Harris (2006)</td>
<td>Partner, Family* Personal care* Residence</td>
<td>Financial Social contacts* Work</td>
<td>Leisure** Religion / Life philosophy**</td>
<td>Sample of males with PD but did have age matched control group (which also included women)</td>
</tr>
<tr>
<td>Conrad, Doering, Rief &amp; Exner (2010)</td>
<td>Intimacy** Achievement** Altruism**</td>
<td>Affiliation</td>
<td>Power Variation</td>
<td>No relationship between duration of disability and life goal characteristics found</td>
</tr>
</tbody>
</table>

**This was significantly higher than for control group**
2.12 Attainability and success

Conrad et al., (2010) and Doering et al., (2011) have added the life goal characteristics of *attainability* and *success* into the body of literature on this topic, since they believe that these additional goal characteristics offer a means of exploring the relationships between executive functions and life goals. They have demonstrated that the subjective wellbeing of patients with ABI depends not only on the appraised importance of life goals but also on their attainability and success. Conrad et al. (2010) found that subjective wellbeing is most strongly associated with success in *achievement* goals, and the discrepancy between importance and success in the *intimacy* domain. However, this study did not consider how success and attainability attributes of life goal domains could change over time, in that their relatively acute sample group included 59 adults with non-progressive neurological disability with a mean duration of disability of only 2.4 months (SD=4.9).

The longitudinal aspects of attainability and success were therefore considered in a follow-up study. Doering et al. (2011) found that outpatients with a longer time since injury reported better daily functioning, but lower subjective wellbeing, when compared to inpatients. Post-hoc analysis demonstrated a close relationship between functional limitations and overall life goal discrepancy scores. They also found that outpatients reported significantly less satisfaction with life, less positive affect, more negative affect and more depressive symptoms than inpatients. Doering et al. (2011) posited that the outpatients might have felt that their disabilities prevented them from realising life goals, but as yet had not adjusted the importance of life goals to the existing limitations. However, this assumption remains speculative and would need to be supported with further longitudinal study data. Kuenemund et al. (2013) also found a significant decline in the attainability and the present success of both communion and agentic life goals over two years following discharge. They felt that this was due to cumulative losses secondary to illness, and to increased awareness of impairments in the post-acute phase. Interestingly, in their data, communion goals showed significantly higher longitudinal decline than agentic goals.
2.13 Impact on outcomes

There is limited data on the efficacy of interventions oriented towards life goals in rehabilitation (Sivaraman Nair, 2003). McGrath and Adams (1999) were able to demonstrate reduced anxiety and stress among subjects undergoing patient-centred goal planning as part of a brain injury rehabilitation programme. They suggested that in a clinical setting, goal planning could assist in coping with distressing emotions by enabling the patient to receive accurate feedback about his or her own performance and progress. They also posited that goal planning could provide realistic expectations about the rate at which goals should be approached. However, results from this study need to be treated cautiously due to a small sample size (n=25), and with only n=8 participants being available for all assessments. There is also a lack of clarity around what actually caused the mood increase seen in patients. It could conceivably be due to a combination of life goal setting and/or a gain in competence and confidence of functional skills due to the delivery of effective rehabilitation. Given the multiple interacting components that make up a rehabilitation intervention (J. Whyte & Hart, 2003), effective ways of determining the outcomes of interventions in the clinical setting remain complex (Kersten, Ellis-Hill, McPherson, & Harrington, 2010). This can make it difficult to specify what particular components are critical to a specific interventions success (Craig et al., 2008). However, research in populations other than ABI has shown that the incorporation of life goals into a management programme resulted in better outcomes in various physical and psychological disorders. In the narrative review Sivaraman Nair (2003a) found evidence for improved outcomes in the following populations when using life goal planning: schizophrenia; end stage renal disease; sports injuries; diabetes; chronic airway limitations and bipolar affective disorder.

2.14 Clinical implications

From this literature review there are a number of emerging themes, reflections and unanswered questions relating to the use of life goals in the rehabilitation of people with an ABI.
Firstly, adaptation to an ABI is a long lasting process (Corrigan & Hammond, 2013; Masel & DeWitt, 2010; Teasell et al., 2012) yet longitudinal research regarding life goals is limited. It remains unclear whether life goal categories and attributes are changed following an ABI, and what impact a loss or change in physical or cognitive functioning may have on life goal attainment, or perception of life goal priorities. It is also unclear how the duration of disability influences life goal adaptation in terms of importance and attainability shifts over the life span and not just in the first two years after injury.

Secondly, life goals identified in literature are broader than those typically set by rehabilitation professionals. Holliday, Cano, Freeman and Playford (2007) found that when individuals were given the opportunity to clearly define and articulate their goals they set fewer goals, but those goals were centred around the individual’s participation in life roles. The patients who had increased participation in goal setting also perceived the goals to be more relevant, and expressed greater autonomy and satisfaction with goal setting. There is strong empirical data supporting the need to particularly strengthen and support *relationships* with partners and other family members instead of only focusing on functional independence (Conrad et al., 2010; Doering et al., 2011; Sivaraman Nair & Wade, 2003b). However, an important clinical question remains: how can we most effectively assist people with an ABI to experience *success* in their relationships?

Thirdly, the current literature suggests that an emphasis should be placed on the vertical coherence of life goals and treatment goals thereby promoting patient’s motivation to fully participate in rehabilitation efforts. Coherence in relation to the hierarchical link between lower level treatment goals and high-level objectives should be made explicit, and alternative strategies and routes to achieve higher-level goals should be planned for in the face of functional limitations (McGrath & Adams, 1999). However, the development and articulation of concrete treatment goals and everyday activities which align with higher-order life goals may pose a difficulty to people following an ABI, particularly in patients suffering from dysexecutive syndrome. Explicit and documented linking of specific therapeutic activities to life goals would appear to be particularly important for those with memory impairments.
Fourthly, the stated importance of life goals of people with disabilities may change over time. Initially it may be difficult to get an accurate picture of a person’s life goals due to cognitive or communication deficits (Sivaraman Nair & Wade, 2003a). In the longer term, many life goals may turn out to be unrealistic or unachievable and people may cope with this by reducing the significance attached to unachievable goals (Sivaraman Nair & Wade, 2003a). In the case of progressive functional loss, some people may realise that they can only achieve a few of their extremely important life goals and therefore reduce the total number of goals they rate as extremely important (Sivaraman Nair & Wade, 2003a). There is, therefore, a need to provide long-term support to people with ABI across the life span, and support them to make changes as required. This intervention may include support with negative emotions due to the slowed rate of, or interruption to, life goal striving or achievement (Doering et al., 2011; Kuenemund et al., 2013; McGrath & Adams, 1999). On-going review throughout the rehabilitation journey is required as the person with the disability demonstrates changes in communication and cognitive ability, improvements in insight and/or awareness, and as changes in the person’s functional status occurs.

There is a large body of evidence showing that successful disengagement from less obtainable goals and re-engagement in alternative goals promotes subjective wellbeing (Neter, Litvak, & Miller, 2009; Wrosch, Miller, Scheier, & BrundePontent, 2007). Coping with the interruption or loss of life goals, and the refocusing on new achievable goals is essential for success. Reprioritisation processes do not appear to happen automatically and on-going interventions aimed at promoting disengagement from unattainable life goals, and exploring ways to engage in alternative life goals, is important to maintain or regain subjective wellbeing in the longer term (Kuenemund et al., 2013). Within the literature, one theoretical model proposed to underpin this reprioritisation process draws on the dual process approach (see Figure 2.4) theorised by Brandststadter and Rothermund (2002). These researchers postulate that there are two mechanisms for goal adjustment: assimilation and accommodation. The assimilative mode is directed at maintaining goals by increasing efforts to prevent or compensate for unsatisfactory life circumstances and situational constraints. In this mode, restitution and compensation approaches are integrated into individual goal hierarchies. For example, effort could be directed to the training of cognitive functions to allow the person to resume previous life roles. Accommodative coping refers to
downgrading the importance of life goals that are no longer attainable in accordance with perceived deficits and losses. Accommodative activities tend to happen over the long term and will gain significance as assimilative efforts fail. “When it becomes evident that premorbidly important goals can no longer be attained despite extensive training and compensatory efforts, counselling therefore needs to support goal disengagement processes” (Doering et al., 2011, p. 532). Successful goal disengagement relies heavily on the availability of alternative goals (Wrosch, Scheier, Carver, & Schulz, 2003) since disengagement will only be possible when alternative goals are established simultaneously.

![Figure 2.5: Dual process approach for resolving goal discrepancies](image)

*Reproduced from Doering, et al., (2011)*

The literature suggests that clinicians should support patients to experience progress in subjectively important goal domains (Conrad et al., 2010; Doering et al., 2011; Kuenemund et al., 2013). This may involve additional effort directed to increase goal success (assimilative mode) *and* support for them to abandon or reframe values and unachievable goals when appropriate (accommodative mode). “Successful assimilation promotes resuming premorbid roles and activities by increasing actual goal success on subjectively important life goals … Accommodative processes only increase in importance as assimilative efforts are failing” (Doering et al., 2011, p. 531). Both approaches will likely lead to reduced discrepancy between goal importance and success and therefore result in an increase in subjective wellbeing.
2.15 Justification for this investigation

Given the importance of person-centred rehabilitation programmes (Cott, 2004; Rosewilliam et al., 2011), one missing perspective within the life goal literature is that of the person who experiences disability. There is the need for further research that explores the goal adjustment processes in the context of severe and complex neurological impairment. This is particularly evident for people with cognitive and communication issues who have a limited voice within the body of published life goal literature. It is necessary to seek to understand how rehabilitation interventions work, thereby building knowledge of how to apply them appropriately across different groups and settings. The voices and perspectives of recipients of rehabilitation services add to the depth of knowledge within the body of literature, helping us to know what questions to ask next and how best to answer them. In this way the ecological validity of a clinical intervention can be better understood and evaluated.

Long term disability challenges a person’s sense of coherence and stability. In this regard, Ellis-Hill et al., (2008) have stated that therapeutic relationships cannot be effective without listening to the individuals – the end users (EU) - and so help to create more positive social realities. It is important that therapists are more aware of, and responsive to the EU experience since this leads to a more informed, nuanced and empathic practice. From this review of the literature it is clear that concepts surrounding the use of life goals in rehabilitation warrant further investigation. Various questions stand out: Do patients perceive an explicit emphasis on life goals as being important, relevant, acceptable and within the scope of rehabilitation services? How do they view the role of rehabilitation professionals in goal planning around life goals? Should life goal assessment be used to only inform goal setting at lower order level, or should they be used as the basis for explicit higher order goals? At what stage do these concepts become important in the career of disability? A person-centred EU perspective will allow future research and theory to be more representative of, and responsive to, the experiences of people who need to access services and support following an ABI.
3 Methodology and methods

3.1 Overview

The purpose of this investigation was to explore the experience of people with complex ABI regarding the role of life goals within the context of being a recipient of residential rehabilitation services. The research was not primarily concerned with life goals *per se*, but with particular people and their *experiences* and *understandings* of life goals. Crotty (1998) stated that it is imperative that we devise a research process that serves our purposes best - one that “helps us more than any other to answer our research question” (p. 216). There is also a need to articulate the research process used in transparent and accountable ways. Such a process provides a description of the methodology utilised within the research, along with an account of the rationale it provides for the choice of methods, and the particular forms in which the methods are employed. “Different ways of viewing the world shape different ways of researching the world” (Crotty, 1998, p. 66). This coherent route from epistemology to theoretical perspective, and finally to practical application, allows for transparency and reflexivity within the research process and ensures that the methods used are driven by consistent philosophy and values (see Table 3.1).

Table 3.1: Methodology and methods as applied to this thesis

<table>
<thead>
<tr>
<th>Research Question</th>
<th>To explore the experience of people with complex ABI, regarding the role of life goals within the context of being a recipient of residential rehabilitation services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epistemological Position</td>
<td>Contextual constructivism - accepts peoples’ meanings as being socially constructed.</td>
</tr>
<tr>
<td>Methodology</td>
<td>Interpretative Phenomenological Analysis (Smith, Flowers, &amp; Larkin, 2009)</td>
</tr>
<tr>
<td>Theoretical Perspectives</td>
<td><em>Phenomenological</em> - explores the individuals’ lived experience</td>
</tr>
<tr>
<td></td>
<td><em>Hermeneutics</em> - recognises the central role of the analyst in making sense of (i.e. interpreting) the participant’s personal experience</td>
</tr>
</tbody>
</table>
Idiography - committed to offering detailed, nuanced analyses of particular instances of lived experience

<table>
<thead>
<tr>
<th>Methods - Data Collection and Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposive sampling</td>
</tr>
<tr>
<td>Semi-structured interviews</td>
</tr>
<tr>
<td>Data analysis at two levels – descriptive and interpretative</td>
</tr>
</tbody>
</table>

3.2 Epistemological position

Our epistemological position relates to our intrinsic beliefs around what kinds of knowledge we deem are possible and how we ensure their authenticity. Epistemology deals with “the nature of knowledge, it’s possibility, scope and general basis” (Crotty, 1998, p. 8) – that is, what it means to know.

Contextual constructivism is a key epistemological position within my investigation (see Table 3.1). It asserts that meanings are not discovered but are instead constructed (Crotty, 1998). Contextual constructivism informs a range of qualitative research programs by suggesting that, “the realities we study are social products of the actors, or interactions, and institutions” (Flick, 2009, p. 70). This assertion contrasts the viewpoint of positivism, which holds that only events that can be observed, or propositions that are testable, have a claim to truth (Smith, 2008). From a positivist perspective, hypotheses are tested, true representations of the world can be tapped, and an impartial observer is able to gain objective knowledge. Truth and trustworthiness are seen as being paramount. However, from a contextual constructivist position, knowledge is seen as local, provisional and situation dependent. Knowledge and reality are subjective, created through social interactions and relationships.

Such a constructivist position fits with my research question, which does not aim to develop a theory but rather seeks to explore and understand people’s experiences. My posture as the researcher is one of an inquirer. The constructivist perspective has congruence with a qualitative methodology in that there is a search for understanding, value is seen in the role of an involved researcher, and the importance of the participants’ voice is emphasised thereby allowing the persons’ experiences to inform new understandings.
3.3 Methodology

A focus on human experience as the central aim of research, or a concentration on construction or interpretation, leads to the selection of qualitative research methodologies (Smith, 2008). Of the range of qualitative methodologies considered, I chose Interpretative Phenomenological Analysis (IPA) for this particular study since “it is committed to the examination of how people make sense of their major life experiences” (Smith et al., 2009, p. 1).

The other main qualitative methodology considered for this research was grounded theory, which emerged from the work of Glaser and Strauss in the 1960s (Charmaz, 2006). The methods used within grounded theory, emphasise the building of inductive theories through comparative and interactive data analysis (Smith, 2008) – the gathering, synthesising, analysing and conceptualising of qualitative data to construct theory. However, my intention was not to extract or construct a theory, but rather to explore in detail how participants make sense of their personal and social worlds. Therefore Interpretative Phenomenological Analysis (IPA) was selected as the qualitative methodology of choice.

3.3.1 Interpretative Phenomenological Analysis

IPA employs a qualitative methodology and is committed to understanding the first-person perspective from the third-person position, as far as is possible (Larkin, Eatough, & Osborn, 2011). It has its roots in phenomenology and symbolic interactionism (Smith et al., 2009) and allows the researcher to “explore, describe, interpret and situate the means by which participants make sense of their experiences” (Smith, 2008, p. 40). In this context, I used the participants’ accounts to reflect upon life goals from the perspective of the participants’ engagement with them.

IPA is concerned with understanding the world from the perspective of the person-in-context, and with exploring the persons’ relatedness to, or involvement in, that world. By using IPA, we commit ourselves to “exploring, describing, interpreting, and situating the means by which our participants make sense of their experiences.” (Larkin, Watts, & Clifton, 2006, p. 110). IPA is based on the concept of contextual
constructivism and adopts three guiding theoretical perspectives: phenomenology, hermeneutics and idiography.

### 3.4 Theoretical perspectives

Outlining our theoretical perspectives allow us to state what our assumptions are - our way of looking at the world. It articulates how we know what we know and makes clear our philosophical underpinnings, further informing our methodology by providing a contextual background.

#### 3.4.1 Phenomenology

Phenomenology focuses on an individuals’ experience and how he/she perceives it, rather than on the development of objective accounts. “It is frequently argued that the main contribution of phenomenology has been the manner in which it has steadfastly protected the subjective view of experience as a necessary part of any full understanding of the nature of knowledge” (Moran, 2000, p. 21). Phenomenology suggests that we allow the phenomenon to be explored from within before imposing an explanation upon it (Moran, 2000). Crotty (1998) stated that “if we lay aside, as best we can, the prevailing understandings of these phenomena and revisit our immediate experience of them, possibilities for new meaning emerge for us or we witness at least an authentication and enhancement of former meanings”(p. 78).

Philosophers who identified with phenomenology are diverse in their interest in, interpretation, and application of, its practice (Moran, 2000). However, IPA sees the cumulative contributions of these theorists as leading to a “mature, multi-faceted and holistic phenomenology” (Moran, 2000, p. 34). There a two branches within the phenomenology literature outlined by Smith (2009). First is the descriptive, existential branch based principally on the writings of Husserl. Husserl sets the conceptual agenda for a focus on experience and its perception. Second is the incorporation of the work of Heidegger, Merleau-Ponty and Satre which moved phenomenology towards a focus on the embodied individual in relationship to their world, and not solely as creatures in isolation. Each branch contributes an additional interpretative dimension to phenomenology by contributing to, “a view of the person as embedded and
immersed in a world of objects and relationships, language and culture, projects and concerns” (Smith et al., 2009, p. 21).

Therefore, IPA is phenomenological in that it is concerned with the detailed examination of human lived experience and enables the experience to be expressed in its own terms, rather than according to pre-defined categories (Smith et al., 2009, p. 32). IPA also systematically and attentively reflects on everyday lived experience, but it is distinct from broader phenomenological philosophy in that it is concerned with experience which is of particular moment or significance to the person (Smith et al., 2009).

### 3.4.2 Interpretivism and hermeneutics

IPA is strongly influenced by the hermeneutic version of phenomenology articulated by Heidegger since, within the IPA framework, analysis always involves interpretation. Hermeneutics recognises the central role of the analyst in making sense of the participant’s personal experience, and in this sense it is interpretative in that it depends on, and is complicated by, the researchers own conceptions and experience. “There is a phenomenon ready to shine forth, but detective work is required by the researcher to facilitate the coming forth, and then to make sense of it once it has happened” (Smith et al., 2009, p. 35).

An interpretivist position proposes that it is impossible to be truly objective since understandings are provisional, partial in nature, and dependent on the context (Finlay & Ballinger, 2006). Instead an inductive approach is advocated, recognising the co-construction of outcome between the researcher and the person being researched. There is recognition that there is no way of neutralising subjectivity as no one is free from societal influences, values, preconceptions and assumptions. Therefore there is a need to make these pre-conceptions explicit so that the reader is allowed to understand and critique the thought processes involved in the analysis of data.

Husserl has suggested that, “we need to *bracket* or put to one side, the taken-for-granted world in order to concentrate on our perceptions of that world” (Moran, 2000, p. 13). Bracketing our current understandings as much as is possible, lets the
experience or phenomena speak to us at first hand (Crotty, 1998). In this way we attempt to set aside our meaning system to the best of our ability thereby making a single minded effort to identify, understand, describe and maintain the subjective experiences of the respondents. Consequently, in my own situation, in a dual clinician/researcher role, it was unrealistic to fully bracket my previous experiences and understandings of both rehabilitation in general, and my relationship with the participants. The experiences and understandings that I brought to the research process had the potential to impact on the way I interpreted the subjective responses and understandings of the participants. Obviously this had the potential to enhance and enrich the data collection and analysis. For example, I have had a clinical role with some of the participants for up to seven years, and this was very helpful within the interviews as I had some understanding of how best to ask questions so as to allow the particular participants (with cognitive impairments) to answer most reflectively. Importantly there was also a need to continually and rigorously examine my own preconceptions and understandings throughout the process of data collection and analysis, and to be explicit and transparent about these. Therefore, cognisant of Heidegger’s views, IPA suggests that reflective practices and a cyclical approach to bracketing are required, since one will not necessarily be aware of all one’s preconceptions prior to embarking on the research (Smith et al., 2009).

Another concept within hermeneutics, highly relevant to this investigation, is that of the hermeneutic circle. This refers to a two-stage interpretation process concerned with the dynamic relationship between the part and the whole. “To understand any given part you look at the whole; to understand the whole, you look to the parts” (Smith et al., 2009, p. 28). Within the interpretivist framework, the hermeneutic circle refers to the need for a dynamic, non-linear style of thinking and so provides a way of thinking about method in IPA – an iterative process involving moving backwards and forwards through the data. In fact, IPA involves a double hermeneutic where the researcher is “making sense of the participant, who is making sense of X” (Smith et al., 2009, p. 35). The journey round the hermeneutic circle is driven by questions evolving from the researcher participating in the double hermeneutic. IPA is therefore interpretative and hermeneutic in that it involves an unfurling of perspectives and meanings. However, as a methodological framework, it is also provides a practical
and coherent approach to the collection and analysis of third person data (Smith et al., 2009).

3.4.3 Idiography
IPA is idiographic in that it is committed to “offering detailed, nuanced analyses of particular instances of lived experience” (Smith et al., 2009, p. 37). There are two meanings of idiographic within an IPA context. The first pertains to individual persons, and the second pertains to their specific situations. Larkin (2006) states that within the IPA body of literature, “…many of its exemplar studies concentrate on specific individuals as they deal with specific situations or events in their lives” (p. 103). The idiographic nature of IPA also means that it focuses on particular nuances rather than making claims about a group or population, by establishing ‘laws’, or making generalisations.

Therefore IPA pursues an idiographic commitment in that it situates participants in their particular contexts exploring their personal perspectives. IPA also starts with a detailed examination of each case before moving to more general claims. In this investigation I held a strong commitment to idiography, in part because people with complex cognitive loss have a limited voice within research literature. Smith (2009) has argued for the value of single case studies and a strongly idiographic approach in qualitative enquiry. In particular he provides justification for the use of a case study to demonstrate existence, not incidence; to point to flaws in existing theoretical claims for a population; and as a means of troubling our assumptions, preconceptions and theories (Smith et al., 2009).

While IPA does not aim to produce generalisable results, it also does not merely retell the participants’ experiences. Instead, “the inductive nature of IPA allows authors to discuss their analysis in the light of varied existing psychological theories models and approaches” (Brocki & Wearden, 2006, p. 96). That is, the interpreter aims to ‘go beyond data’ to draw out an explanation. With the move away from viewing disease and illness solely within a biomedical model, there has been an increased recognition of the constructed nature of illness and disability. IPA allows us to “explore these subjective experiences, and helps us to describe and understand the respondent’s
account of the processes by which they make sense of their experience” (Brocki & Wearden, 2006, p. 88).

3.5 Methods for collection and analysis of data

Besides epistemology, methodology and theoretical perspectives, there is a need to consider the methods used in this investigation - by which I mean the research strategies employed to collect and analyse the data.

3.5.1 Participant recruitment

To be included in this investigation, participants needed to be aged 18 – 65 years as I wanted this study to focus specifically on working aged adults. They needed to have a brain injury (e.g. traumatic brain injury, stroke or subarachnoid haemorrhage) that they acquired in adulthood (i.e. after 18 years of age) and still be involved in active goal-directed rehabilitation. All participants were required to have experience of a neurological disability for greater than one year, thereby ensuring that they had had some time to experience life with disability and to reflect on their ability to achieve their life goals. Participants were required to have a basic level of understanding of their situation – specifically, they need to know that they were in a rehabilitation service for an injury or illness they had suffered – and they needed to be able to hold a conversation in English. Other than that, third-party evaluations of potential participants’ level of insight, cognitive function, or communicative abilities were not used to exclude people from the study. Indeed, it was the intent of this investigation to actively recruit people with cognitive impairments in order to explore with them how they articulated and strove toward achieving their life goals (if at all).

Recruitment of participants was by way of purposive homogenous sampling (Smith et al., 2009) from within the rehabilitation centre. All potential participants were first approached about the study by a third party (i.e. a clinical colleague not otherwise involved in the research), who asked whether the individual in question would give verbal consent for me to discuss the study with them and to invite them to participate. Prior discussion with these third party colleagues was used to identify the kinds of
people who would be potentially suitable for the investigation (i.e. the sort of people who met the inclusion criteria).

All potential participants were given an information sheet about the study, written in layperson’s language. Research contact information was also included in this sheet (see Appendix 3). The third party colleague read through the information sheet with the participant, and also gave them a copy to discuss with family, or to read through later. Participants were given a minimum period of five days in which to consider whether they wanted join to find or to find out more about it.

If the participants agreed, I then met with them and provided a fuller explanation, answering any questions they had. At that point, or after being given further opportunity to reflect, written consent was obtained (Appendix 4). An additional copy of this consent form was given to the participant for their records. For participants with reduced capacity for decision-making (as determined by having an Enduring Power of Attorney (EPOA) in place and enacted), additional consent was also obtained from the person acting as their EPOA (although this was only required for one case). In total, seven people were invited to be part of the investigation, and of these, five agreed to participate. Of the two who did not agree to participate, one did not follow up on the initial invitation and was therefore not approached again. The other person verbally declined after being given the information sheet.

In consultation with my supervisors, and in response to the quality and richness of the emerging data within the interview narratives, a decision was made to recruit five participants in total. Consistent with IPA methodology that allow for smaller sample sizes, this allowed for deep analysis around the convergence and divergence of themes as they emerged.

3.5.2 Data collection
IPA aims to collect data inductively in a way that, as far as is possible, enables a person’s experience to be expressed in its own terms, rather than by predefined category systems. Therefore, individual semi-structured interviews were used for data collection in this investigation. Semi-structured interviews are a flexible data
collection system that facilitate rapport, allow greater flexibility of coverage, allow interviews to go in novel directions and tend to produce richer data. The questions are open ended, singular, and non-directive to minimise the researcher influencing the participants’ responses to too great an extent. The use of semi-structured interviews in the IPA framework is common; however there are other options that have been used, such as focus groups, diaries and electronic journaling. These various data collection options were considered, and at times offered for specific participants, however were not utilised.

A schedule for the semi-structured interview was constructed in collaboration with my supervisors. This schedule aimed to facilitate a comfortable interaction while also enabling the participants to provide a detailed account of their experiences related to life goals and rehabilitation. In the schedules initial development, the main aims of the study were grouped into a series of open-ended questions and were used in a position interview, where I was interviewed about the investigation by one of my supervisors (KAS). These key questions were also discussed with my primary supervisor (WL). Further questions were developed after re-reading an annotated bibliography undertaken previously, and were then reworded into more open, reflective questions and prompts suitable to ask people with brain injury. A copy of the interview schedule is included in Appendix 5. The initial question within the schedule was broad so as to facilitate rapport and to allow people to tell their story as if meeting me for the first time. The rest of the interview was in two parts: the first part explored what life goals were important to the person and how these may have changed in response to his or her ABI, and the second part explored the role of life goal planning within the participant’s own rehabilitation journey.

There were changes to the content and sequencing of questions throughout the process of data collection, and within each interview, since the interviews were guided as much as possible by the participant. At times there was the need to be more directive when interviewing the participants due to cognitive, memory and/or language impairments (Smith, 2004). This included using more prompts, summarising what had been covered earlier in the interview to ensure that they remembered the key life goals they had identified, and checking and re-checking with the participants the consistency of their responses within the interview itself. Prompt sheets (Appendix 6) were
developed in the schedule development stage, however were not required in any of the interviews.

Interviews occurred in an environment familiar to the participant as a means of facilitating discussion and adding support to its genuineness and congruency. In all cases the participants chose to be interviewed in their bedrooms, even though other options were suggested. The interviews ranged from 50-80 minutes in length. Short breaks were included in some of the interviews to allow for toileting. Fatigue was an issue for the majority of participants as evidenced by the reduced quality and richness of the verbal responses near the end of the most of the interviews. This was addressed by allowing the participants more time to respond and repeating or rephrasing questions as required.

All interviews were digitally audio-recorded, and then transcribed verbatim by an externally contracted typist. Identifying information was removed from transcripts (e.g. names of people, places and service) to protect the participants’ confidentiality and a pseudonym was used on all documentation to ensure depersonalisation of the data. All written data was stored in a locked cabinet at the researcher’s home office, and electronic versions of the transcripts were kept on a secure computer with a password known only to the researcher.

### 3.5.3 Data analysis

Analysis of the data was undertaken following recommended IPA strategies (Smith et al., 2009). IPA utilises a cyclical iterative process of analysis in which the researcher approaches the data idiographically - beginning with particular examples and slowly working up to more general categorisations or claims as the investigation progresses. Analytic processes within the IPA framework are largely unremarkable when compared with other qualitative methods. Larkin (2006) has suggested that it “may be more appropriate to understand IPA as a stance or perspective from which to approach the task of qualitative data analysis, rather than a distinct method” (p. 104).

At the core of analysis lies an emphasis on the experiential claims and concerns of the person taking part in the study. Building on the recommendations of Larkin (2006), I
approached the data with two objectives in mind. In the first instance I tried to understand the participant’s world, and to describe _what it was like_ as if seeing it for the first time. This was particularly important given my on-going clinical role. At a secondary level, I then developed a more overtly interpretative analysis, which positioned the initial description in relation to a wider social and cultural context. This second-order account aimed to provide a critical and conceptual commentary upon the participants’ personal sense-making activities. It was therefore more speculative in that it explored what it meant for the participants to have made these claims, and to have expressed these feelings and concerns _in this particular situation_. Finally, the themes and their meanings were examined alongside findings from existing research, to question and support my interpretation of the data. Table 3.2 outlines the lengthy process undertaken in the analysis of the data – a systematic and cyclical process of reflection, identification, description, clarification, interpretation and contextualisation (Larkin et al., 2011). While IPA avoids being too prescriptive about how data analysis is performed, certain recommendations are made that highlight the need for rigorous immersion in the interview data, an iterative and cyclical approach to analysis reflective of the hermeneutic circle, and the maintenance of attention to the idiographic nature of the analysis (Smith et al., 2009).

### Table 3.2: Stages of analysis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Action</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Journaling my own reactions and biases before, during and after each interview.</td>
<td>To enable a clearer understanding of my perceptions as they arose, and to assist with later interpretation and analysis of the transcript data.</td>
</tr>
<tr>
<td>2</td>
<td>Transcription of digitally recorded interviews by externally contracted typist. Formatted into three column template and depersonalised.</td>
<td>To allow for analysis using IPA recommendations.</td>
</tr>
<tr>
<td>3</td>
<td>Transcript checked by listening to the digital recording. Pauses, emotions, and fillers were added to the transcript (as per transcription conventions)</td>
<td>To immerse myself in the interview data, and to check for transcript accuracy.</td>
</tr>
<tr>
<td>Stage</td>
<td>Action</td>
<td>Rationale</td>
</tr>
<tr>
<td>-------</td>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td>4</td>
<td>Line by line in-depth analysis (multiple times) of paper version of the transcript.</td>
<td>First-order analysis (descriptive) conveying an empathic understanding of the experience, and second-order analysis (conceptual) based on deeper interpretative work.</td>
</tr>
<tr>
<td>5</td>
<td>Individual interview analysis codes added to NVivo 10 (QSR International).</td>
<td>Software designed to assist with managing and analysing qualitative data.</td>
</tr>
<tr>
<td>6</td>
<td>Summary documents outlining themes for each individual participant sent to supervisors for comment.</td>
<td>To ensure that rigor is maintained. This triangulation, by means of multiple member checking, was aimed at providing consensus rather than absolute agreement.</td>
</tr>
<tr>
<td>7</td>
<td>Themes from each interview were combined together in NVivo 10. These subthemes were then printed out and clustered manually into overarching themes.</td>
<td>On-going second-order (conceptual and interpretative) analysis looking for convergence and divergence across emergent themes, and for deeper layers of meaning.</td>
</tr>
<tr>
<td>8</td>
<td>Use of Microsoft Word document to assemble quotes and connecting ideas. Each node, with supporting quotes, was reviewed and added where appropriate.</td>
<td>Development and confirmation of supraordinate and subordinate themes.</td>
</tr>
<tr>
<td>9</td>
<td>Development of written results into a narrative.</td>
<td>To develop themes and deeper levels of interpretation.</td>
</tr>
<tr>
<td>10</td>
<td>Re-reading, and listening, to the original transcripts. Reading forward to develop the</td>
<td><em>Idiographic component:</em> re-read transcripts to ensure that a focus is maintained on the individual experiences of the participants. <em>Interrogative component:</em> read</td>
</tr>
</tbody>
</table>
An audit trail of memorandums, journal notes, stages of analysis, and audio-conference notes were maintained to demonstrate reflexivity and transparency. My journal included reflections on my role as both a clinician and researcher, and how the interactions with participants throughout the interviews might have been affected by my particular communication style, vocabulary and values. Other processes that were used to support reflexivity included: discussing my progress, emerging interpretations and analysis with my supervisors on a regular basis; meeting with my clinical advisor after interviews to discuss emerging clinical or ethical factors; having each transcript read and independently commented on or coded by one of the supervisors to aid robust discussion around emerging themes; and presentation of preliminary results at a rehabilitation postgraduate student seminar followed by a discussion with one of my supervisors.

### 3.6 Ethical considerations and risk management

#### 3.6.1 Ethical approval

An application for review of this investigation was submitted to the Upper South Regional Ethics Committee on 24 April 2012. This application included an overview of the research question and background to the study, the proposed study protocol, a copy of the patient information sheet and consent forms, as well as discussion of the risks and benefits to people participating in the study. Notably the existing therapeutic relationship between me (as the primary researcher) and the potential participants for the study was identified. This application was reviewed by the chairperson of the Upper South Regional Ethics Committee, who concluded that full ethic committee review was not required due to the low risk nature of the study (according to the
National Ethics Advisory Committee’s (2006). A letter confirming this was sent on 22 May 2012 (see Appendix 8).

The Upper South Regional Ethics Committee did however suggest that the organisation in which the investigation was to be carried out (i.e. the rehabilitation facility in question) may specify their own processes regarding notification or approval of the study. I therefore contacted the Chief Executive Officer (CEO) of the rehabilitation facility, advising of the anticipated ethical issues around the proposed research (providing the same information as given to the Regional Ethics Committee) and asking if the organisation required any further assurance around potential ethical issues that had been identified in the design stage. The CEO approved the investigation in person, and no further information was requested.

Despite the study being identified as low risk by the Upper South Regional Ethics Committee, attention to ethical issues was still taken very seriously during the investigation. This included the following:

- Meeting with the CEO of the research facility throughout the research process to discuss potential ethical issues as they emerged.
- Regularly fortnightly discussion of the study and any potential ethical issues arising with my thesis supervisors, as well as email discussion when required.
- Participation in regular meetings with a clinical advisor throughout the research process - an experienced occupational therapist (not one of my supervisors and external the clinical environment) to talk about and reflect on clinical issues arising from the study.

An overview of three particularly relevant issues, which had potential ethical implications, is outlined below.

### 3.6.2 Role of the researcher

Within IPA there is recognition of the dynamic role of the researcher within the process of both data collection and analysis. In this specific study, I have worked with all the people currently receiving slow stream rehabilitation at the rehabilitation facility in a clinical capacity. In this setting, slow stream rehabilitation involved providing ongoing therapy for people with severe impairments who have a reduced
rate of learning or an inability to engage in therapy of high intensity. In some instances I was providing oversight clinical physiotherapy input at the time of data collection (i.e. monitoring the types of therapeutic activity that individuals were involved in, but being not actively involved in providing those therapeutic activities). While this assisted with the rapport between the interviewer and interviewee, and arguably the richness of data obtained, there was also the potential for confusion around boundaries and expectations. This issue was rigorously considered in terms of consent, participant sampling and in the process of data analysis.

In response to the ethical concerns around boundary issues, the following protocols were put in place. As already discussed, a third-party person gained verbal consent for me to approach each potential participant. As part of the consent process the participants were made aware of the position I held within the residential centre. The participants were also offered the opportunity to have another interdisciplinary therapist to coordinate their rehabilitation programme. The participants were provided with an external contact if they had any questions or concerns, and the information sheet also made it clear that participating in this research would not affect the participant’s current or future health care (positively or negatively) in any way. There was regular discussion with my clinical advisor regarding any potential for role conflicts from the researcher/clinician interface. A debrief with a research supervisor and/or clinical advisor occurred after each interview in order to examine any immediate reactions and biases. The supervisors also reviewed the interview transcripts. Finally, I recorded my own reactions and biases before, during and after each interview, to enable a clearer understanding of my perceptions as they arose.

3.6.3 Emotional risk and managing distress

Each participant was informed of their right to nominate a whānau member or support person to be present during interviews, and full consideration was given to any sensitive issues that could arise during the research period. It was anticipated that participants might become distressed throughout the course of the interview. If this occurred, the plan was to inform the participant that they could stop the recording themselves, or ask for it to be stopped, at any stage. Participants were also regularly informed of their right to decline to answer any questions or to withdraw from the
study. Support from a social worker, clinical psychologist or other nominated staff-member at the centre was made available, and external support was also offered. However, none of these supports were required during the study.

3.6.4 Cultural considerations and consultation

“The place of rehabilitation for indigenous people requires particular attention given the health need, demographic profile and most importantly the right to participate in and receive quality health and rehabilitation care” (Harwood, 2010, p. 972). In the New Zealand context, it is important that Māori are able to access services based on good quality research and evidence, and that their experiences are incorporated into the development and delivery of best practice in rehabilitation. Submission of this research proposal was made to the rehabilitation facilities cultural committee. No participants self-identified as Māori within this study. Nevertheless, this research included the following protocols, based on the three guiding principles of Te Tiriti O Waitangi:

- **Partnership**: self-identified ethnicity data was gathered via a demographic data collection tool as per the Ethnicity Data Protocols for the Health and Disability Sector (Ministry of Health 2004).
- **Participation**: results that appeared relevant to Maori were to be highlighted and reported back to the appropriate consultation group, and/or Maori health providers, for wider dissemination
- **Protection**: recognition was given to any cultural expectations and I sought to meet these expectations responsively and respectfully.

3.7 Summary

The aim of this investigation was to explore the lived experience of participants, regarding the role of life goals, within the context of their being a recipient of rehabilitation services. This chapter has examined the theoretical and paradigmatic underpinnings within this investigation, and has discussed the methodology and methods used to answer the research question. IPA was chosen because of its commitment to exploring, describing, interpreting, and situating the means by which people make sense of their experiences. The theoretical frameworks underlying IPA
are phenomenology, hermeneutics and idiography. The epistemological perspective of this study aligns with a contextual constructivist paradigm. Five people with complex ABI were recruited and participated in a semi-structured interview. In-depth data analysis was undertaken using IPA strategies. Attention has been drawn to some key ethical and pragmatic issues that evolved during the collection of the data and its subsequent analysis. The results of the data analysis are discussed in the following chapter.
4 Results Chapter

4.1 The participants

Five people were recruited and interviewed. The demographics outlined in Table 4.2 are pooled in order to help maintain anonymity. The sample was homogenous in that all participants had a long term, complex disability as a result of an adult ABI. Their impairments, in combination with social factors, required that they all reside in a residential care facility providing rehabilitation services. The time since injury ranged from one year to 36 years. Three of the participants had ongoing physical impairments as demonstrated by the Barthel Index. All participants had significant cognitive and executive functioning deficits including difficulties with abstract reasoning, problem solving and planning. All of the participants had marked memory impairments impacting on their ability to recall events within a day, and for one participant, within a 10 minute interval. The participants also demonstrated limited insight and awareness, along with impulsivity. Three of the participants had marked difficulties with spatial and geographical orientation. Four of the participants lived in the main residential facility and one participant lived in one of the Active Support cottages.

Table 4.1: Pooled participant demographic information

<table>
<thead>
<tr>
<th>Variable</th>
<th>Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Women = 3</td>
</tr>
<tr>
<td></td>
<td>Men = 2</td>
</tr>
<tr>
<td>Age range</td>
<td>51 – 62 years</td>
</tr>
<tr>
<td>Time since injury</td>
<td>1 year 4 months – 36 years</td>
</tr>
<tr>
<td>Time in current facility</td>
<td>1 year – 33 years</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Traumatic brain injury = 2</td>
</tr>
<tr>
<td></td>
<td>Stroke = 3</td>
</tr>
<tr>
<td>Barthel Index Scores</td>
<td>Score of 10: n=1</td>
</tr>
<tr>
<td></td>
<td>Score of 55: n=2</td>
</tr>
<tr>
<td></td>
<td>Score of 100: n=2</td>
</tr>
</tbody>
</table>
4.2 Overview of themes

This chapter presents the results emerging from the transcripts of semi-structured interviews with five participants. The analysis focused specifically on how participants made sense of their experience of life goal planning and achievement while receiving goal-directed rehabilitation within a residential facility.

Table 4.2: Summary of emerging themes

<table>
<thead>
<tr>
<th>Supraordinate themes</th>
<th>Subordinate themes</th>
<th>Emerging concepts</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Being part of things’: actively integrated, connected and encountering</td>
<td>The ‘most important thing’</td>
<td><em>Intimate</em> connectedness through family relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Relational</em> connectedness through friendships</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Collective</em> connectedness through citizenship</td>
</tr>
<tr>
<td>‘Unchanged, changed and changing’: self in the context of life goals following an ABI</td>
<td>Unchanged</td>
<td><em>Rapid change</em> (“bang”)</td>
</tr>
<tr>
<td></td>
<td>Changed</td>
<td><em>Gradual change</em> (“can’t get back to my old ways of living”)</td>
</tr>
<tr>
<td></td>
<td>Changing</td>
<td><em>Ongoing</em> process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>New scripts reflecting an <em>evolving self</em></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Evolving <em>strategies</em> used towards goal achievement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Retaining / rebuilding <em>hope</em> but also facing <em>reality</em></td>
</tr>
<tr>
<td>‘Opportunities arising’: The influence of environmental context of life goal achievement</td>
<td>Attention to life goals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Connections with social networks</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The value of meaningful occupation and participation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Systems and processes</td>
<td><em>Risk</em> management</td>
</tr>
<tr>
<td></td>
<td></td>
<td><em>Role of staff</em> as facilitators or gatekeepers</td>
</tr>
</tbody>
</table>

Three supraordinate themes emerged from the analysis (Table 4.1). The first theme is named ‘**Being part of things**’ and relates to the desire for all participants to be **actively integrated, connected and encountering** within their social relationships and as citizens of the world. Within this theme there is a strong subtheme of being
able to contribute to relationships, through the enacting of roles, rather than just being in receipt of care and support.

The second theme is named ‘Unchanged, changed and changing’ and relates to the participants own self in the context of life goals following an ABI. This theme incorporates the idea of the person having a complex presentation of being unchanged in terms of the life goals which remain important to them, while also at the same time being changed significantly in both sudden and more slowly emerging ways since their ABI. The final subtheme relates to the ongoing change, growth and development that the person experiences as they learnt to live with their changed self over the longer term.

The third theme is named ‘Opportunities arising’ and relates to the influence of the participant’s milieu on life goal achievement. This theme explores the various contextual challenges, and opportunities that the participants experienced in life goal identification and achievement, while undergoing rehabilitation within a residential context.

These three themes are connected as shown in the following balance-board graphic (see Figure 4.1). The desire for social connectedness (‘Being part of things’) emerged as a central theme for the participants. But in order to achieve this important life goal there was a need for the participants to constantly balance their self concept (as explored in the theme ‘Unchanged, changed and changing’) with their environmental context (as explored in the theme ‘Opportunities arising’). In the clinical setting, the balance-board is often referred to as a wobble-board. Within this investigation the term wobble-board gives reference to the tentative and dynamic nature of the complex interactions between the three emerging themes as experienced by the participants.
4.3 Theme 1 – Being part of things: actively integrated, connected and encountering

This first theme is titled ‘Being part of things’: actively integrated, connected and encountering’ and includes the following subthemes: intimate connectedness through family relationships, relational connectedness through friendships and collective
connectedness through citizenship. A key theme that emerged from the data was that participants perceived being in relationship with others as being the ‘most important thing’. Being involved in relationships, and being connected and integrated, was talked about as an important life goal by all of the participants. In this context being connected related to having close social relationships with people, including family, friends and wider community networks - as opposed to having a relationship with other things such as nature or a higher divine being. Participants made sense of themselves in terms of their experience of themselves in social and activity contexts – whether they were feeling part of things. When I asked Megan how she would express her life goal in a picture, she stated:

*I think I’d show other people with smiles on their faces, because I had encountered them.*  
[Megan]

Within this supraordinate theme three subthemes emerged: intimate connectedness through family relationships, relational connectedness through friendships and collective connectedness through citizenship.

All the participants described the importance given to intimate connectedness through family relationships. Social support within families, and relationships between family members, were valued highly in relation to their experience of life goal achievement.

*In here I want to rehabilitate myself to the extent I can go home, and be in a home by myself, and have my son. And come back to being a stay-at-home mum again. And doing the right thing by my boy.*  
[Sarah]

Participants described themselves as wanting to be available for their families. For Sarah this was seen most prominently in her desire to “be there” for her children...“no matter what”. In this context Sarah expressed a clear goal of being a reliable mother who is able to offer her children unconditional love - and not being a mother who “let’s [her] children down”. Megan also echoed the sentiment regarding “being there” by providing guidance and life skills advice to her children.

*I’ve been able to help my son and daughter ... I’ve been able to sit down and talk to them about it, very honestly and openly, and made them see that it’s not the end of the world if that happens, that it’s just a small part of their lives, and they will work through it. So I have been able to do that, and that’s given me huge joy.*  
[Megan]
Being able to perform the role of provider was important for participants. John, in particular, described the importance of being able to provide for his family by purchasing the meat for the family Christmas meal, and by offering them financial gifts. For Bridget, being able to cook a meal for her son was also highly valued.

Use of the words “home” and “house” also appeared repeatedly though the data. These terms appeared to suggest a safe space for the participants – a place of security – that in turn, allowed for meaningful relationships and connectedness. The words also seemed to reference a sense of place. Of being anchored both in a physical location, and also in relationships.

I just want to get my own home. And get me, [my son], and – and settle, and just be comfortable, and be peaceful. That’s all I want, is just some nice peace in my life. [Sarah]

Physical closeness and proximity appeared to facilitate this experience of connection for all of the participants.

Included within this theme was the notion that reciprocity in relationships and encounters within the family unit were positive for both the participant and the whole family. Intimate connectedness provided a way for the person with the brain injury to contribute to the family system.

They’re the only family I’ve got... so I’m going to look after them. They look after me. I look after them ... for birthdays and Christmas, I give them two hundred dollars each... and a lovely Christmas card. And I- I accept nothing in return. Only friendship. [John]

However, there was also reference to a downgrading of expectations around the level of contact required to maintain a perceived close family relationship. This was particularly evident when I asked John how often he was in contact with his mother who lived overseas.

P: All the time.
I: How often would you talk to her?
P: Oh, every six months or so. [John]

Relational connectedness through friendships was also an important identified life goal. Important concepts that emerged through the analysis of the interview transcripts
included a desire for relationships outside the residential context, spontaneity in friendships, the practical support offered by friends, and the importance of friendships in helping the participants perceive a sense of belonging. Positive supportive relationships contributed to a person’s perception of meaning and purpose, and contributed significantly to a strong self concept for all of the participants.

A desire for personal relationships and social connection with people outside of the residential care setting was a significant theme throughout Simon’s interview. Simon particularly wished to reconnect with friends from his past - especially those that he knew prior to his brain injury.

[I’d like to see] some more friends outside of the [facility]. I try and catch up with some of my old friends I haven’t seen for many years. I don’t know how. A lot of them have gone now. [Simon]

Regular, spontaneous contact that occurred between participants and friends was valued by a number of participants and was reflected on by Bridget who felt that she had achieved this with her friends.

Just ringing them in the odd day, and [my friend] comes in quite a bit and sees us. [Bridget]

Friends also appeared to provide participants with a means to gain instrumental support and assistance, and these friendships allowed participants to feel part of a social group. Friends provided a facilitatory role in brokering social connectedness so that the participants felt included and part of things. Simon felt that friends also allowed him to be “social and busy” and this helped provide structure to his days and weeks.

The value frequently placed on the longevity of friendships appeared to be linked to the participants need for continuance between their pre-injury and post-injury selves, and contributed to coherence across the lifespan. For example, John described the importance of his friendship with a woman from his past.

She rings me up to make contact. I’ve known [her] going back how many years. You know, it’s great that we’re friends like that. To have good friendships like that. [John]
For John, the continuity and coherence that this friendship provided was vital to his sense of self after acquired disability. Through this friendship he was able to demonstrate that he was “a sensitive person” – which was a central part of John’s self-concept.

A further emerging subtheme related to collective connectedness through citizenship. In this sense the participants saw themselves as people who were contributing to something larger than himself or herself, or to another person. This was in contrast to only receiving support. Megan referred to this succinctly in a number of ways. “I want to be somebody who’s contributing, not demanding help all the time”; “I’d like to be somebody who’s caring, of other people, and the world in general” and “I would say my interest in being able to interact and care with other people would be my top notch first wish”. For the participants, the purpose of caring for others was not just to ‘give advantage to’ or assist the other. Megan saw her role as being an advisor, guide or mentor, and she was able to give an example of how she was able to do this with her children since she had her brain injury. For Bridget her part-time work provided an important avenue for contributing to others.

A prominent concept emerging from the interview narratives was that by helping others, the participants were also helping themselves and gaining from the experience.

It’s very important to me to be able to help people. Because given that I’m – it’s obviously good for them that I’m helping them, but maybe this is selfish, it’s very, very important for me that I’m helping them. [Megan]

One aspect of being a ‘citizen of the world’ related to seeing one’s issues and self in a larger context. For John particularly, this appeared to help him to positively reframe his own situation.

I: Is there anything here within [the facility] that you can do on your own, that you - is important to you?

P: I don’t know - is there anything? I don’t know. (Long pause) But you know, I love - I love the world, you know. [John]

Throughout the interview John consciously redirected his thoughts from his personal struggles and goals, to a wider global perspective. He talked about how seeing the news “made [him] cry” and how he wished to travel the world one day to “see the
sights”. This self-articulated “love for the world” appeared to help John to positively reappraise his own situation, providing a broader appreciation of life.

In summary the high value that participants placed on relationships was related to the desire to have a sense of belonging and to encounter with others. This was accomplished through the giving and receiving of support – both instrumental and emotional support. Within the context of these relationships participants experienced meaning and purpose. This sense of purpose contributed to the participants emerging view of themselves in terms of their self-identity, but was also connected to the meaning attributed to their day-to-day activities. Also, the participants all described a desire to retain or build relationships outside of the residential facility environment.

The following quote from Megan’s interview links the first theme of ‘Being part of things’ to the other two themes: ‘Unchanged, changed and changing’ and ‘Opportunities arising’.

P: So in terms of getting back to my old ways of living, as such, that hasn’t really happened at all.
I: So do you think you’d be able to explore a bit more why you think that might be that it hasn’t happened that way?
P: I suppose it hasn’t happened that way because the opportunity just hasn’t arisen. I haven’t made the opportunity for myself. I’ve just sort of stagnated, in some respects. Trying to cope with my new physical state, and my living away from my family, and away from doing everything family-oriented, I found myself quite isolated. And because of that, I haven’t had the opportunity to pursue those types of things.

[Megan]

As shown in Figure 4.1, within these two subsequent themes are factors that need to be constantly balanced to achieve social connectedness. As evidenced by Megan’s quote they include concepts pertaining to the participants’ own self concepts, as well as barriers and facilitators within the participants’ milieu.
4.4 Theme 2 – Unchanged, changed and changing: self in the context of life goals following an ABI

This theme relates to the person’s understanding of self in the context of life goals following an ABI - the participants’ views of themselves as unchanged, changed, and also continuing to change across the lifespan. An emerging understanding of self-identity was strongly associated with this theme, arising from the participants’ experience of personal consistency and change after disability. There was also the notion of on-going movement and change that continued across time, reflective of the participants’ growth and development as individuals.

The **unchanged** subtheme incorporates the participants’ perception of the coherence between their current self-concept and life goals, and their view of themselves prior to their injury. There was coherence between the things that mattered to them most in the past, and what was important to them in the present. The participants described this coherence in terms of their life goals, such as the importance of home, helping others, being integrated in relationships and not stagnating. Some participants also described this coherence particularly in relation to their own selves – their personality, personal strengths, insecurities and skills. For example, Bridget described herself as previously being an “outgoing” and “loud” person who just “just wanted to get up and do things, get things done”. When asked if she would describe herself in a similar way now, she responded:

> I’m probably still a bit loud. I like going to see friends, that sort of thing. And going out. [Bridget]

However, a frequent emerging theme was the difficulty that participants often had connecting with their past selves due to memory impairments. The participants described difficulty remembering what their past goals were. Bridget for instance spoke of the impact of her memory impairment on recalling and celebrating previously highly valued skills and achievements. Once I reminded her of her past interests (by referring her to photos in her room) she stated, “I miss that”.

> P: Can’t really remember what [my past interests] were.
> I: Right. Yeah. (Long pause)
P: I was the only woman in New Zealand [competing in a particular sporting event]... used to race against the guys. Oh, it was good. Yeah, I loved that. I forgot about that. Yeah, no, it was good. [Bridget]

Although the participants described a view of being unchanged in some aspects of themselves, there was also recognition that they had changed considerably in other ways. Megan described herself as being “terribly different”. For Megan, this was reflected in a sudden sense of dependency on others for physical assistance. She described her experience of not being able to use the left side of her body and the impact this had on her independence with physical tasks.

Its left me with a feeling of what I’d say is almost utter defeat, given that I am so incapacitated. And I’m not an independent person anymore, I mean I literally need people to help me get dressed. And to help me get in and out of bed. And so I’m terribly dependent now, on care. And I find that very frustrating, because I was a very independent person previously. I mean I had very lovely relationships with people that would help me with certain things, but it wasn’t an absolute need to be helped as it now is, unfortunately.

[Megan]

Megan also recognised that while she saw herself as unchanged, her ability to achieve her life goals had altered. When asked whether the things that were most important to her had changed, she replied:

No, I’d say they are pretty much the same, but it’s my ability to be able to achieve them which has changed. [Megan]

This theme is further divided into concepts around sudden change and gradual change following an ABI. Sudden change related to the immediate impact of the ABI while gradual change referred to the on-going and less immediately obvious changes that emerged over time, which were more related to a changing understanding of oneself.

Megan talked about the sudden change she experienced in the following way.

[I] found out how- you know, easy it is just to bang, one minute you’re there, next minute you’re whole life’s turned upside down. [Sarah]
The sudden changes were often talked about in physical terms such as “incapacitated”, being “stuck in a chair”, and being “dependent”.

I: What were the things that you found difficult?
P: Oh, couldn’t speak, walk, or- yeah, it’s horrible...not nice at all. [Bridget]

These, therefore, referred to activity limitations as a direct result of the sudden onset of impairments and were reflected in a sudden sense of dependency on others for physical assistance.

However, there was also the experience of gradual change over time in which people gradually grew to perceive an inability to return to their life before ABI. There was an awareness that they would not be able to get back to their old ways of living. This was experienced by the participants as dependence on others for physical tasks contributing to a loss of agency, a changed view of self, and an inability to utilise coping strategies from the past. Over time this eventually led the participants to feeling stagnated and isolated.

The participants’ sense of loss of physical independence was mirrored by an experience of loss of agency. The loss of decisional and executional autonomy gradually led to participants feeling like they were being a burden to others in their social world.

When you are very debilitated, and dependent on people... you feel like you’re being a burden. Not that anybody ever indicates that here, ‘cause they never do, but I worry that I am being a burden. And it’s the last thing in the world I want to be. I want to be somebody who’s contributing, not demanding help all the time. [Megan]

Not being able to act in “normal” ways also contributed to the participants’ sense of a loss of control and choice. For Sarah this was apparent in her inability to garden - a previously important occupation for her. But it also related to her inability to fulfil her past parental role – providing alternative life experiences for her son including accessing outdoor activities and experiences, as well as being part of his daily routine.

It’s my daughter when she comes in and I can’t go home with her, and my son, seeing my son, and having to let him go home with my daughter and me not go. And know that I’m not going to be there later at home. And I can’t- I don’t
take him to school, and I don’t pick him up from school, and that really bothers me. [Sarah]

For Megan there was a clear understanding and recognition of her need for physical assistance, but also for her wish to make independent choices. She was also fully aware that her ability to be independent was complicated by her “physical state” but not determined or restricted by it. That is, while she acknowledged the limitation that her physical impairments placed on her, she also understood that these should not restrict her ability to make independent choices and have control over her environment.

Unfortunately, if I was to set off down the drive, and go round a few streets, I would be- it’s frightening to think this, but I would be completely lost and bamboozled about how on earth I got back to [the facility]. I think ‘Oh, where am I?’ and ‘Where’s [the facility]’ and I would struggle really seriously to be able to retrace my steps... I can’t just make that decision and head off. I’ve got to arrange to do it, and ask if I can do it, and ask somebody to accompany to do it. And they are all restrictions on your freedom, really. [Megan]

Despite this self-awareness, Megan still described a perception of struggle, as well as a feeling of being shackled.

I’ve always wanted to be somebody who’s been able to interact in any way that I can with the world, and with other people, and again, of course, that’s now extremely limited, because I’m wheelchair-bound, and not free to come and go here, there, and everywhere - as I wish I was. So I suppose I just feel a bit shackled, unfortunately. I don’t resent it, ‘cause I understand it’s for my own benefit, and I understand I need to be, but I do regret that I need to be. [Megan]

So Megan’s sense of independence with her decision-making and choices was very limited; “instead of being able to trek off in my wheelchair, and just nip down to the shops” she needed to request permission and assistance from others.

The experience of gradual change also manifested through the participant’s changed view of themselves and the changed perceptions of their family. An example of this
gradual change was expressed by Sarah, who described it in terms of an increased awareness of fragility.

Well, I know I’m a strong person, I’ve always been quite strong but, I just- you know, and lately I find that if I sit and think about my son, or different things that have gone on in my life, I could actually sit and just cry. [Sarah]

An emerging understanding of the impact of memory difficulties also resulted in Sarah feeling less sure of herself, which in turn threatened her self-identity.

It’s just certain things that um, that my daughter will talk to me about and then I- she’ll come and see me and talk about it again. And I’ll have no memory of it, but I’ve- she; has actually told me. And that disturbs me a little bit, ‘cause I don’t want my children to think that I’m a forgetful old nanny. You know what I mean? So yeah, that does upset me a little bit. [Sarah]

Likewise, Megan described a growing experience of change in who she had become following her brain injury. She described herself as “somebody who’s caring of other people and the world in general.” However, this idealised view of herself was in conflict with her current reality, which led to a feeling of disappointment “… because I know I have got the ability to help people, and I think it’s rather a waste that I’m not doing so”.

Finally, as part of the subtheme gradual change, participants also described not being able to use old coping strategies, leading to changed ways of operating. For example, Sarah described herself as being “stuck in her chair”, and how her sudden physical impairments had led to an inability to enact coping strategies as in the past. These changed ways of operating led to the use of alternative strategies and routes to life goal achievement. Prior to her ABI it appears that Sarah had been a spontaneous decision maker – reacting to life circumstances and challenges in an ad-hoc manner. This was no longer workable for her and had resulted in her needing to learn new skills, including problem-solving and step-wise goal achievement.

[Be]cause before if I was living in my home what I’d do is just look for another one. And I’d just do it, whereas I can’t do that here. I have to get to a certain stage, physically, and probably mentally as well, in my life at the moment, before I can go and get my own home, I- and that’s a big- big big difference for
me, cause when I wanted my own home I’d just go out, look for it, and go and get it.

[Sarah]

These gradual changes appeared to lead to a sense of stagnation and isolation for most of the participants. Sarah recounted a recurring dream that evoked this feeling of isolation for the participants.

Like being in bed at night and I have this dream, and I wake up, and I think that my [children] are actually here, and I actually call out their names. And they’re not here. And that really is disturbing.  

[Sarah]

Simon’s interview was also richly reflective of this notion of disconnection and isolation in relation to the absence of friendships. There was a pronounced sense that life had moved on without him.

I: Those friendships that you had when you were younger have sort of-

P: - dissolved a bit.  

[Simon]

Megan described herself as previously having “lots of roots, and friends in [the city I used to live in]” prior to her ABI, but now saw herself as “dependent and isolated” rather than being “very independent, and very integrated into the world”. When asked if she felt that she had been given opportunities to be caring and giving towards others, as per her most important life goal, she responded:

Unfortunately not very, because I lead- given that I am living here, and living away from my family even, I have a very isolated existence. So I don’t even know of the people I could reach out to.  

[Megan]

This gradual change for Megan also led to everything requiring more effort. She described how she was “trying to cope with my new physical state” and how this had severely impacted on her ability to get back to her “old ways of living”. The additional physical effort of living had made it difficult for her to have reserves to take action on life goals – a situation which had become routine for her, and which caused her to feel unfulfilled as a person; as if she was not living life to her full potential.

It makes me feel- I suppose the best way to describe that is it makes me feel terribly restricted. It makes me feel like I’m not living my life to the full extent that I ought to be.  

[Megan]

However, this perception of isolation was not the case for all participants. Bridget described herself as being extensively connected to her son and friends, and to others
through her paid employment. Bridget never indicated that she felt herself to be a burden, or to be isolated and dependent. A lack of decisional or executional autonomy was not described by Bridget who expressly talked about how she was able to “come and go” as she pleased. In part this was related to a lower risk profile for Bridget around disorientation when compared to other participants in the study, but may also have been related to different environmental contexts and an alternative Active Support model of care in the cottage in which she lived.

The final subtheme, changing, is connected to an emerging understanding of self in the context of life goals following an ABI. It relates to the on-going change and development that continues throughout the life span of the person with an ABI. This concept of evolving and growing is in contrast to a more static view of a person who has achieved their maximal physical recovery and whose progress has supposedly plateaued. Within this subtheme are concepts related to: a sense of on-going progress; the appreciation of the creation of new scripts reflecting an evolving view of self; the evolving use or non-use of strategies towards goal achievement; and retaining/rebuilding hope while also facing reality.

Firstly, the participants talked about being in a state of on-going progress and recovery. Simon discussed improvements in his memory that had occurred over time, and Sarah and Megan both referred to improvements in their independence with personal care tasks. Bridget referred to her past inability to “walk, talk, or do anything” and contrasted this with the statement that: “now I’m working”. However, she had on-going concerns around how well she was expressing herself verbally. At the end of her interview for instance, she sought validation by asking “I did okay? Did I?” and talked about the difficulty she had “putting things into words… into sentences and that.”

Not all participants however felt that they were making consistent or substantial gains over time. This was particularly evidenced in the interviews with Megan and Simon. Simon articulated a perception of being completely “off track” with his life goals around friendships and socializing. This reflected his experience of being stuck in the past – with no improvements in his ability to make friends. Megan described feeling “disappointed” in her inability to reach out to people, and “sad” about her inability to
enact independent decision-making. For Megan there was an awareness within her interview that there had been no change in these issues for many years.

For people who were further along the journey of recovery following ABI, there was still a sense that they only had tenuous control over their physical selves. Their experience was that physical skills would remain a focus for goal selection in rehabilitation over the longer term. For John this was reflected in his day-by-day control over his continence and in the phrase “I do this morning” within the following excerpt.

P: But other than that, you know, it’s a perfect life. You know, being alive, and I know my medication, that sort of stuff...and all my bowels and stuff.

I: Your bowels. Yeah, so you’re feeling like you’ve got some control over your body?

P: Yeah. I do this morning, you know. Other than that. This is a great life. [John]

Megan also referred to a need to constantly retain some focus on the maintenance of physical skills. For Megan, physical issues were on-going and could never be ignored. When I asked her to clarify her comment that there had been too much focus on her physical needs within her rehabilitation, she replied:

P: Well in a way [there had been too much focus on my physical needs], but on the other hand, unfortunately, it is still very relevant, because I’m still incapacitated to the same degree, I can still not move the left side of my body at all, and I can’t therefore dress myself, or walk anywhere or do anything like that. So I am still a wheelchair-bound, very dependent person. So of course those cannot change. [Megan]

Secondly, there was the appreciation of the creation of new scripts reflecting an evolving view of self. These scripts appeared to be related to life goal choices for the participants. Sarah’s thoughts reflected the significance that she gave to the emergence of a new self-identity and narrative around this identity:

Well before my [ABI] I was um, because of all the horrible stuff that I was going through, I was a drinker, used to drink a lot. So I don’t want to do that anymore ... I don’t want to have to rely on my drink to get rid of my problems
and my thoughts, and to be happy again. I don’t want to do that anymore, ever again. [Sarah]

Sarah described herself as being “more determined now, since I’ve had my [ABI]” and as having the need to be protective of herself with a stronger appreciation of her need for boundaries. There was also an increased awareness of her need to be self-reliant. Other participants also appeared to appreciate the changes that they have seen in themselves over the years since their ABI. John referred to his development as a moral person. For Bridget this personal development was recognisable in her being less impetuous than in the past.

I: In what ways do you think you might be different?
P: Oh, well here I’m sort of more settled. If you know what I mean.
I: Can you tell me a bit more about that?
P: Well I’ve got a- this is like a home.
I: Yeah. So you feel sort of quite- (pause)
P: Yeah. Safe and yeah. Yeah, no, it’s good. [Bridget]

Thirdly, the evolving use or non-use of strategies towards goal achievement emerged from within participant’s narratives. There was reference to participants often having practical solutions to problems and barriers if they were asked. For instance, Megan recognised her need for interdependence and factored this into a possible solution to her wish to help others.

Well perhaps ... if I could find a charity that needed my types of help and skills. If I could be assisted in going to it, in other words, if I could offer my help. But I would unfortunately of course need some help myself. So if there could be somebody sort of in the background, as it were, to come and be able to help me whilst I’m helping others. [Megan]

Megan was able to evaluate her life goals and modify pathways to achieving them so as to make them more realistic and achievable.

Not all participants were able to identify possible strategies to progress towards their life goals however. Simon, for instance, was unable to come up with ways of widening his social network, and instead had to rely on other to pursue such objectives.

I: So how do you go about making a new friend?
P: That I’m not sure about. (long pause)
I: Mm ... Tricky, isn’t it.

P: Mm hm. [Simon]

In this interview, Simon described being almost completely dependent on his coach to provide the content and structure for his day. This extended to facilitating engagement. When asked what he would include in his ideal day, Simon replied a number of times that it “depends on what [the coach] has got planned for me”. Within the interview transcript there was an impression that Simon was unable to work towards life goal achievement without significant levels of external support.

The participants’ levels of self-efficacy were in part revealed through their response to questions during the interviews. This understanding was based around whether participants were actively working towards goal achievement or whether they were passively hoping for change. Megan had a strong perception of her need to take ownership of her goals, make “opportunities” for herself, and to drive her goals forward.

I think just thinking to myself ‘come on look, missus, is this really all you want out of life?’ And goading myself to express no, that’s not all I want of life, and therefore okay, if it’s not all I want out life, ‘come on then, make an effort to do something about it.’ It comes just sort of like a pep talk for myself, really. [Megan]

Sarah on the other hand articulated a mixture of internally and externally held factors that led to her feeling motivated. On one hand she used terms such as “I’m trying-doing everything I possibly can”, “do my damnedest” and “I’ll use that to my best ability”. On the other hand she tended to have a fatalistic stance when thinking about goal achievement. This was articulated in a repeated phrase within her interview, “knowing my luck”.

Retaining/rebuilding hope but also facing reality was the final concept emerging from analysis of the subtheme changing. This related to the inter-relationships between retaining or rebuilding hope; facing the realities of on-going impairments and activity limitations; and the emerging impact of aging.

Retaining or rebuilding hope was a key concept emerging from the data. For John, contemplating travelling the world was important to him and connected him to
something larger than himself. He also articulated an on-going desire to walk again despite having been wheelchair dependent for some decades, and despite a growing awareness of his mortality. John simultaneously held hopes for probably unachievable outcomes along with hopes for more generalised but potentially more achievable states of being. For example, John stated that he did not “want to be disabled all my life, but I suppose I am” and also recognised his physical loss of walking. Walking was clearly a significant loss for John and emerged repeatedly throughout the interview.

I’d like to get out of this chair and run down the hallway. And things like that you know what I mean?... that’s impossible to – that’s an impossible task. You know.

[John]

Therefore, while he wished to walk, he did not necessarily expect that this would occur. Therefore in this case John appeared to demonstrate hope as a want or desire, rather than hope as an expectation. Likewise, Sarah continued to dream about creating a safe home for her son, and to provide him with a range of outdoor experiences such as camping and fishing despite her significant on-going physical impairments. She also continued to think about future roles she might inhabit, such as being “a nana”. This appeared to offer her significant hope. Within this understanding of hope was a feeling of gratitude for what she did have and an on-going focus on the positive aspects of her life.

Ambiguity between current reality and future hope seemed to be linked to changing expectations and the downgrading of goals by the participants. This was evident in John’s downgrading within the interview when talking about his main ambition in life being to “have a happy marriage. Or if that doesn’t work out, a happy partner, or someone that- you know what I mean.” Part of this downgrading of expectations was around timeframes. There seemed to be a shift from a more concrete hope for recovery, to a more generalised hope for the future, as participants adapted to living with an ABI over the longer term.

There was the notion that life moves on, as explored previously within the changed theme - participants were no longer sure what life would be like if they did achieve their stated life goals. Being disconnected from real life situations and contexts had resulted in them being unable to determine how their life goals needed to evolve and change to reflect the changes in themselves, their families, and society in general. In
part, some participants were unable to imagine what their life goals might be. For Sarah particularly there was also some uncertainty about how the relationships that she aspired to would impact on her current situation. There was almost the view of life goals around relationships being disembodied wishes that did not relate to her current context.

*Would be nice to have a partner, but I have no idea there.*  

[Sarah]

For John the impact of aging and awareness of his temporality was a significant factor in his self-identity.

*Oh, I’m turning an ancient. Ancient now. Ancient.*  

[John]

John referred to an awareness of the passing of time and the impact of this on the possibility achievement of his life goals on a number of occasions throughout the interview. He recognised his finite life and was beginning to incorporate this within his life goal priorities.

*Because I might pass away tomorrow, I might never see the sights at all. You know what I mean?*  

[John]

John was also starting to acknowledge the impact of aging on his likelihood for achieving his life goals.

*I’m getting older as years go by. But I reckon I’m not too sure how I would succeed in that.*  

[John]

Developing alternative means for achieving goals was also evident. For example, John identified a long-term goal to go on a world trip but also recognised the financial and physical barriers to achieving this. He had therefore been able to achieve part of that goal in a different way, by travelling to a different part of New Zealand on a couple of occasions.

In summary the theme ‘Unchanged, changed and changing’ captures the experiences of the participants changing and developing representations of self. The participants changed abilities, and changed view of self, contributed to a sense of stagnation and isolation. However, the theme also incorporates the on-going change, growth and hope experienced by the participants. Nevertheless within the interview narratives the participants also referenced a need to continually balance their own unchanged, changed and changing selves with the environment that they inhabited (see Figure 4.1)
so as to achieve social connectedness – their most important life goal. This is reflected in the final supraordinate theme.

4.5 Theme 3 – Opportunities arising: the influence of environmental context on life goal achievement.

This final theme related to the way participants made sense of the challenges and opportunities for goal identification and achievement within their specific life context. The four main subthemes that emerged from the data included: attention to life goals; the impact of a lack of connections with social networks; the value of meaningful occupation and participation; and the influence of residential systems and processes on life goal achievement.

Within the subtheme attention to life goals, there was some ambiguity around whether participants felt that life goals were actually discussed or addressed in residential rehabilitation. Both Simon and John expressed the view that the interview for this study was the first time that life goals had been discussed with them. Megan also described feeling as if there had been a sole focus on physical rehabilitation during her recovery, and that life goals had not featured in her rehabilitation to date.

*Unfortunately I’d say they haven’t featured at all. Cause my rehabilitation has pretty much been physical rehabilitation. So in terms of getting back to my old ways of living, as such, that hasn’t really happened at all.*  
[Megan]

This was not a consistent experience for all participants, however some participants, including Sarah, felt that attention to life goals had featured in their rehabilitation planning. Sarah talked about an imminent move into a self-care unit that she felt addressed the life goals she had already communicated to staff.

*Yeah, there is- there is coming up, when I go into that unit, there’ll be a lot. And it’ll be really good for me, because it’ll teach- show me what I need to actually do to be in my own home. And if I need to buff up on any of my skills, as far as being in my own home goes. So that will actually be quite good.*  
[Sarah]

Specifically the move to the self care unit, with the increased challenges of living more independently, was seen by Sarah as offering a link to her key life goal of being able to
provide a safe home for her son. Bridget was also clear that her important life goals had indeed been discussed and considered in her on-going rehabilitation plan.

One concept that emerged from this data related to the impact of memory on life goal retention. This related to what the participants’ life goals had been prior to their ABI, and what they were at the time of the interview.

I: So do you think that your goals of what’s really important to you in your life have changed since your ABI?

P: Can’t really remember what they were. [Bridget]

The impact of memory was also described in relation to whether life goals had been discussed in the current context. When exploring whether attention to life goals had contributed to the establishment of his yearly goals, Simon stated:

P: I think it does.

I: ... so in what ways do you think the staff support you to have more friendships?

P: Not sure.

I: Can you remember any of your specific goals around friendships and things?

P: I can’t- not off the top of my head, I can’t. [Simon]

For Megan, her memory impairments played a significant role in her ability to share her goals with other people.

I would say it almost certainly does, yes, because on a daily basis, and for instance now we’re talking about it, it’s really in my mind, and I think ‘oh yes, this is very important to me.’ But, come tomorrow, I will have- don’t mean this to be rude, but I would have sort of forgotten this conversation. ... And therefore I won’t think to raise it with anybody. [Megan]

All of the participants described the value of discussing life goals with staff. For some there was a belief that it was a necessary and vital part of achieving a good understanding between the staff and client. John talked about a sense of importance of staff knowing him as a whole person.

P: Oh, it’s good, it must be good for you too.

I: How do you think it might help us?
P: Express my feelings. About different subjects, and different tasks, and you know. [John]

Participants also described some reluctance about sharing their life goals with staff. One important theme that emerged from the data was a desire to not burden staff.

Well I suppose I don’t like to prattle on, you know, people are helping me, on my day-to-day necessities, and I don’t therefore want to burden them with ‘oh, but I really want to be doing this.’ I should- I feel I should be grateful for, and encourage the help in the ways that I do get it, because of course it is invaluable to me to get that help. And I don’t want to diminish that in any way. [Megan]

Participants perceived that raising the issue of life goals was placing too much expectation on the staff, and instead that they should just be grateful that staff were helping with the basic daily tasks associated with self-cares. Another reason for some reluctance to share life goals related to the perception that staff would not place the same high value on the goals that clients held. Simon was explaining that he thought his life goals were only important to him when he stated:

P: I think [that the life goal] is. It’s may- not to anyone else, I don’t think.
I: Not to anyone else though?
P: No, just to me. [Simon]

A further emerging subtheme related to the participants’ ability to initiate and sustain connections with their social networks and wider community, thereby allowing, or providing barriers to, meaningful interactions.

The participants frequently described feeling isolated from their social networks. For Megan this was described as the physical and emotional distance resulting from “not living at home”. There was an awareness that not being in the same physical location as her family had provided some challenges and had stood in the way of natural opportunities for connection to occur. For Sarah this was expressed in relation to how not seeing her son on a daily basis meant that she did not “have him in my life”. However, it was clear that it was the daily contact, rather than physical proximity, that was most lacking and problematic for Sarah, due to the resulting emotional distance.
Bridget also valued the daily contact between herself and her son, and recognised the role that staff and facility processes had in ensuring that this occurred. While Simon wished to reconnect with the friends he had prior to his injury, he also described difficulties he had in finding, and remaining connected, with new friends.

*I:* Would you feel comfortable inviting someone in to visit you here, and hanging out?

*P:* mm hm.

*I:* You would feel?

*P:* Just can’t find anyone to invite back.  

[Simon]

Memory loss could also be isolating for participants, particularly in the residential setting where there were a large number of people to get to know. Simon described this when talking about the time he first moved into the facility.

*I:* Yeah.  So how was that change for you?

*P:* Bit difficult to start with.  I’m getting there.

*I:* What was difficult?

*P:* Remembering all the names is one thing.  Cause I got a very bad memory.  I had.  It’s coming right though, thank goodness.  

[Simon]

An emerging theme described by the participants was the importance of being situated within relationships and social networks as a means to maintaining ones’ own motivation.

My family, definitely.  And also if I see anybody that needs any sort of help at all, that also motivates me.  

[Megan]

However, the experience of living in the residential environment was not always negative for the participant. Aspects of the current residential setting also helped some of the participants to feel motivated.

Um, seeing some other residents that are here that are worse off than I am, and I sit, and I think about that, and I think well, imagine what they would be like if they were in my position.  And they’re actually physically worse.  So then I do feel a little bit better off yeah ... And then I think right, well now I know what I’ve got to do, and I don’t want to be like, so I’ve got to get stuck in and do this.  And that gives me a bit of motivation as well.  

[Sarah]
In relation to motivation, being in a residential rehabilitation setting were described as not only being beneficial to the participant. There was also an understanding that the participant could contribute to others by inspiring them through the modelling of goal directed behaviour and through their own achievements.

*And just to show that it can actually be done to the other residents. If they’re actually taking any notice - it can be done. And just hopefully that just helps put them into a space where they think right, if she can do it, so can I.*

[Sarah]

Opportunities for **meaningful occupation and participation** were also highly valued by the participants, who provided examples of when they had developed and consolidated new, adaptive, and personally salient meanings through occupational roles. The opportunity to participate in activities that allowed some level of independence also appeared to be important to participants. Work roles, whether paid or voluntary, also provided an avenue for social connection.

Simon described the enjoyment and social connectedness he experienced when previously working as a volunteer. The value of occupation was also particularly clear for John. He described an experience of accomplishment and pride in his weekly woodworking activity:

*I go to [woodwork]. Twice a week - Monday and Thursday. And I really love going. I love doing things with my hands, you know. And making the [shelves] for my wardrobe. Put all my stuff in. Not the sanding down though.*

[John]

John also referred to the enjoyment he received from creating leather products for sale. He described the creation of physical objects as being good for “keeping [his] mind occupied”. He appeared to particularly value the ability to participate, using the phrases “I like to”, “I do”, and “I’m proud” extensively when talking about his achievements. John described having a sense of self involved in, and emerging from, the activities he was engaged in.

For Bridget, the value of occupation was most clearly viewed through the lens of her vocational role. Her part-time employment allowed her to experience “the independence of working” and facilitated her connections with people.
The people I work for – work with, and the customers- the residents come in for meals, I can chat away. Yeah, no, it’s good. Really good.

I: Why is that good?

P: Being friendly. That sort of thing. Yeah. [Bridget]

Paid employment provided her with many opportunities. These included opportunities to acquire financial resources, opportunities for social interaction, opportunities to contribute to the lives of others, and opportunities to make clothing choices. Increased choice and control, increased executional autonomy, and increased financial independence were critical for Bridget. Financial independence was, in particular, expressed as being the second most important life goal for Bridget. Earning her own money allowed her financial flexibility and enabled her to pay her own way, particularly in social situations where previously she had been reliant on her friends paying for her activities and meals.

I: What was difficult? What did it feel like when you had [to rely on others to pay for things?]

P: Oh. Horrible. Yeah, I didn’t have any money to do this, or do that. Go and buy bits. Yeah. [Bridget]

For Bridget, money was also seen as facilitating her involvement in other important life goals, such as saving for a holiday with friends. Therefore money allowed Bridget to make choices in small day-to-day decisions, and this contributed to her ability to achieve her life goals.

In summary the meaning and the doing, within the occupational roles undertaken by the participants, appeared to be intrinsically linked. Both the importance of the specific task, and the social interactions within the task environment, contributed to the achievement of life goals for the participants in this study.

Systems and processes within the residential facility could act as facilitators or barriers for the participants. This subtheme is made up of two interconnecting concepts: risk management systems versus choice and control; and the role of staff as facilitators and/or gatekeepers.

Risk management systems and processes within the organisation were closely associated with the participant’s opportunity to attain and maintain autonomy, choice
and control. For the participants, cognitive impairments, particularly around memory, orientation and initiation, were significant factors impacting on daily function. Extensive risk management planning had been put in place to identify and manage risk effectively for all of the participants. This was to be expected for this group, given that the need for 24-hour support was often the primary reason for their living in this particular residential setting in the first place. Nevertheless the participants described a lack of opportunities, or barriers, to enact decisional autonomy.

For Megan, her inability to make a decision to purchase an item of clothing without seeking staff permission or support was a significant restriction to her “freedom of independence”. When discussing what type of life would be important to her, Megan stated:

Well I think to be able to make independent choices about how I want to spend my day, for instance, and where I want to go, and to be able to just do it, without having to beg and plead. Is it okay if I do that? – type of thing. And then have to get somebody to accompany me to do it.

[Megan]

Megan had an awareness of safety issues and understood the need for risk management processes. Nevertheless, this lack of ability to make spontaneous decisions contributed to a loss of choice and control over her daily activities.

Sarah, who stated that prior to the ABI she had been quite spontaneous in her decision-making, with a “just do it” attitude, echoed this sentiment. Simon also described some of the difficulties he experienced when wanting to leave the residential facility to visit people.

I: So what stops you at the moment going out to visit people? From here.

P: [My coach] is the one thing, I can’t always find him. [I need him to be able to] use one of my taxi vouchers. [Simon]

It therefore seemed that within the main facility, and for people with more severe cognitive impairments, decisional autonomy was difficult to achieve, even though this independence of choice remained an importantly held value for the participants. In contrast, Bridget, who lived in the area using an Active Support model of care, frequently referred to her ability to “come and go as I please” and talked about a number of ways that she was able to enact choice and control through her contribution...
to the running of the household, connections with her friends and son, and in her personal shopping.

The **role of staff as facilitators or gatekeepers** in supporting the participants was also closely aligned to the concepts of choice and control as outlined in the previous section. Staff members within the facility were perceived as contributing to, and limiting, actions towards life goal achievement. Bridget saw the staff as being both unnecessary and facilitatory. On one hand, Bridget perceived that she required little support from staff to enact her choices in daily life.

   *I:  So what sorts of things are you needing support from [the coach] with at the moment? What sort of things is she helping you with?

   *P:  Nothing.  [Bridget]*

However, at the same time she recognised that staff provided strategies for her to achieve what she wanted to do within each day, and also helped her come up with new ideas for meaningful activities to pursue.

   *Oh, [the coach] gets us doing things.  [We’ve] got our own garden, vege garden, and that sort of thing.  [We] have daily planners she does for us.*  

   *[Bridget]*

Her experience of staff support appeared to point to the staff as being in the background providing *just enough* support to ensure that she was able to participate fully in her daily activities, without requiring extensive and overt facilitation.

Support from staff was vital to ensure that John sustained connections within the wider community and within his social networks. However, even with this support it would seem that the regularity of his encounters was somewhat limited. Similarly, Simon was fully reliant on others to assist him in initiating and sustaining connections with social networks and the wider community. There was a clear sense that Simon was living a mediated life with limited ability to express choice and control in his daily tasks and activities. This appeared to relate, in part, to risk management and minimisation processes in that Simon described some of the difficulties he experienced when wanting to leave the residential facility to visit people. However, he also appeared to be very dependent on staff to initiate and facilitate daily activities and tasks, and to determine the content of his day.
I: So if you think ‘oh, I’d like to catch up with some old friends,’ what would you do about it?

P: Figure how I can go about contacting them.

I: Would you ask for any support from anyone to do that?

P: I could ask [the coach], I suppose. (long pause)

I: You’re not sure?

P: Yeah, I’m not sure actually whether I can ask him.

I: Why do you think you might not be able to ask him?

P: Mightn’t be available.

Simon appeared to view his coach as being a gatekeeper who limited and controlled his options. Simon’s experience was suggestive of a lack of control over the resources needed to achieve his life goals. Interestingly, the concept of a lack of control appeared to extend to even being unable to choose where his lives.

[The funder] wouldn’t let me live alone. So I need a place like this to look after me.

Megan referred to having to “beg and plead” in order to enact her choice in how she wanted to spend her day. She appeared to feel the need for staff to sanction her choices. She was dependent on others to action intentions and required physical support to facilitate decisional independence. However, a key barrier identified by Megan was that she did not want to ask for more support than was offered. Her experience was that permission had not been given to tell staff about her life goals. She therefore did not identify these issues as being within the remit of her current rehabilitation programme.

Participants also described the importance of external validation from staff, including the need for recognition of mastery over small goals when describing their successes. John provided an example of this when he talked about how proud he was of his woodworking.

It’s really great doing what I do. I’m proud of what I do, you know. And so is everybody else.

Sarah demonstrated a reliance on external guidance for specific strategies that could be used to achieve her life goals.
Because I need them to realise exactly what I’m trying to go. And what I’m trying to aim for. So that they able to help me in all the right ways. And show me ways that I can reach my goals.

Sarah was referring to staff at the residential facility when she stated that “they...can’t have as much faith in me as I have in myself”. This was indicative of her belief that staff did not feel that she was able to achieve her goals and therefore were not validating of her. Sarah talked about the need to share her ideas with staff, and the importance she placed on telling them her goals. Bridget also identified the support of staff and friends as being important at keeping her motivated by providing strategies to continue a high level of engagement and participation in daily activities.

An important concept emerging from the data, was whether staff were perceived as being supportive of the small gains made by the participants, and how these related to the participants longer term life goals. The participants suggested staff seldom expressed the view that their life goals were achievable. Sarah particularly perceived a need for staff to reiterate her goals, congratulate her on small achievements, and to minimise the difficulties she was facing. The perceived lack of support and encouragement for the small gains appeared to hold deeper significance than just those specific moments of goal achievement per se; instead it appeared to impart a lack of faith in the whole person (“faith in me”).

I have more faith in myself as far as getting- achieving what I need to achieve to get into my own home. And I will do my damnedest to actually get there. And I – and I know- and I have faith in myself – know that I will actually get there. And my children have faith in me as well. So- and that’s something that I just need to do cause I don’t want to let my kids down either. [Sarah]

In summary, this theme explored the participants’ experiences of the environmental facilitators and barriers that they encountered in relation to the conceptualisation and attainment of their life goals. Issues related to whether attention was (or was not) given to the articulation of life goals have been raised. Difficulties connecting to social networks, the ability to engage and participate in meaningful occupational roles, and organisational systems including risk management processes and staff, were highlighted within the interview narratives. These factors all contributed to whether or not opportunities arose for the participants to engage in life goal orientated activities.
4.6 Chapter summary

This chapter has outlined the three supraordinate themes that emerged from the data so as to describe how participants experienced life goal achievement following an ABI. In line with a commitment to an ideographic approach, attention has been directed towards an account of each participant individually before moving to more generalised claims. The generalised themes of ‘Being Part of Things’, ‘Unchanged, Changed and Changing’ and ‘Opportunities Arising’ are distinct yet dynamically linked together to describe the whole experience of the participants.
Discussion and conclusion

5.1 Overview

The purpose of this investigation was to understand how life goal planning and achievement was experienced within a residential rehabilitation service. This discussion will explore the findings of this study with regards to existing literature, and identify areas for future rehabilitation service development and research.

The supraordinate themes captured how participants’ perceptions of the facilitators and barriers to life goal achievement were connected and dynamically balanced. Within the results, the importance of ‘being part of things’ emerged as the central theme. A dynamic interplay was evident between interpersonal factors related to an unchanged, changed and changing self, and the residential milieu in which the participant lived. In this discussion I argue that the participants’ narratives in the present study support a growing body of literature that points to an increasing need to focus on the role of social identity and the environment in the delivery of rehabilitation services for people with ABI.

The first key position taken within this discussion is that if we are to support people to achieve their life goals following a severe ABI, then we will need to continue to develop theoretical frameworks and interventions that better support people in terms of social relationships and social identity throughout their lives. The second key position taken within this discussion is that there is a need to keep a focus on the assumption that a person’s milieu is susceptible to change even after severe ABI, and that people in residential care require increased environmental support and creative solutions to facilitate life goal attainment. The final section of this discussion proposes some recommendations for providing a rehabilitation service that can better support people to live well with a brain injury throughout their lives.

While the current research findings are not novel, they do add to the existing body of life goal and rehabilitation literature by exploring the experiences of people with a severe ABI who require residential support. They also contribute to the articulation of
what person-centred service delivery (Cott, 2004; Leplege et al., 2007; Rosewilliam et al., 2011) may look like for this population.

5.2 Relationships are important

The importance attributed to life goals within the relationship and intimacy domains emerged repeatedly from the interview data. While an ability to independently manage personal care and residential or domestic arrangements also featured as important life goals for the participants in this study, they considered social relationships and connectedness as having primary significance. This is consistent with previous studies around life goals that demonstrated the high importance given to relationships by people with neurological disability (Conrad et al., 2010; Kuenemund et al., 2013; McGrath & Adams, 1999; Sivaraman Nair & Wade, 2003a, 2003b). Within the current study social relationships were viewed in relation to intimate connectedness within the family, relational connectedness within friendship networks and collective connectedness through citizenship and contributing to others.

Participants described relationships with others as being highly important in satisfying their fundamental need for belonging. However, there are multiple conceptualisations, definitions and theories around social inclusion, social connectedness and social relationships within the literature. In a qualitative meta-analysis, Hall (2009) considered social inclusion in its broadest sense and found that social inclusion for people with disabilities consisted of three elements: involvement in activities, maintaining social relationships and a sense of belonging.

The concept of sense of belonging has been used in numerous disciplines. Mahar, Cobigo and Stuart (2013) conducted a narrative literature review to develop a transdisciplinary conceptualisation of social belonging with a focus on intellectual disability. They reviewed papers from education, mental health, cultural/ethnic identity, disability, and religion fields. Based on this review, they defined a sense of belonging as being,

“a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs and personal characteristics. These feelings of external
connectedness are grounded to the context or referent group, to whom one chooses, wants and feels permission to belong. This dynamic phenomenon may either be hindered or promoted by complex interactions between environmental and personal factors.” (p. 6)

Crucially, they found that achieving a sense of belonging involved more than solely perceiving oneself as being socially included. Instead it also incorporated aspects of feeling attached, feel valued and having a sense of being an insider (E. Hall, 2010).

Within the current study there were a number of concepts related to a sense of belonging emerging from participants narratives. ‘Being part of things’ contributed to a sense of normality and of fitting in, both of which supported the person’s sense of self. The participants’ sense of connectedness was also related to reciprocity – shared feelings, experiences and understandings. Being able to contribute to others, and not just being in receipt of care was a further aspect of reciprocity talked about by the participants. While paid carers emerged alongside friends and family as facilitators of social connection, there was also a desire to have friends and activities in the wider community and away from the residential context. Social connectivity also appeared to lead to the accessing of opportunities.

Self-identity has recently become a focus in ABI research literature (Gracey et al., 2008; Levack et al., 2010; Muenchberger, Kendall, & Neal, 2008; Nochi, 1998; Pallesen, 2013; Ylvisaker & Feeney, 2000). The term self-identity relates to a multi-dimensional internal representation of the individual. Self identity influences the choices of goals in life, and helps people make sense of the lives they lead (Douglas, 2013). Changes in physical, cognitive, emotional and social functioning can have a profound impact on the person’s conceptualisation of self and the ability to reconstruct a sense of self after brain injury (Douglas, 2013; Levack et al., 2010; Nochi, 1997). Identity construction thus becomes central to rehabilitation (Klinger, 2005). Within the results this was reflected in the theme ‘Unchanged, changed, and changing’

However, within rehabilitation literature there is also an increasing understanding of the importance of social identity (Gracey et al., 2009; Gracey et al., 2008). Social identity theory (Tajfel & Turner, 1979) suggests that participation in social contexts is the means by which we realise our identities (Haslam et al., 2008). Douglas (2013)
explored how adults after a severe TBI conceptualised themselves between five and 20 years following their injury. There has been limited research on the experience of people who have sustained a severe injury. Douglas’ sample group had similar demographics to my own sample, although they all lived in the community rather than in a residential setting. The first two themes within Douglas’ work described a model of self-conceptualisation, while the third key theme captured the participants’ experience of factors that helped them to create and maintain a sense of connection between the conceptualised self and society. In Douglas’ research family, friends, carers, pets, as well as concrete reminders of social connection (social snacks), all contributed and supported this sense of connection. Haslam et al. (2008) have also highlighted the importance of social identity continuity as a predictor of mental health and adjustment to changes after a stroke. It is therefore important to not just consider the conceptualised self in isolation. There is also a need to consider how social identity contributes to sense of self and wellbeing.

A clear relationship exists between self- and social- identity within the literature. The loss of sense of self after injury is accompanied by a reduction in the individuals’ social activity (Nochi, 1997). Douglas (2013) has provided insight into the importance of maintaining social connection and social engagement as facilitators of a positive outcome after TBI. Gracey et al. (2008) looked at the personal construction of self-identity following TBI and emphasised the important roles that social and practical activity played in the personal construction of self after injury. Levack et al. (2010) conducted a metasynthesis of qualitative research around the experience of recovery and outcome following TBI, with loss and reconstruction of self-identity emerging as a key finding. More generally, it appears that group identification fosters positive social relationships and, as a result, is a precondition for good health and wellbeing (Jetten, Haslam, & Haslam, 2012b). However, in the ABI population, it has been shown that goals reflective of the intimacy, affiliation and altruism domains tend to be perceived as being less attainable, and are less likely to be successfully achieved, over time compared to other life goals (Kuenemund et al., 2013). I propose that there is a need to support people in relation to a social world – not just in personal meaning making, which is separated from broader social contexts. Rehabilitation services should broaden their focus from functional status rehabilitation to include social identity.
considerations. Therefore, the achievement of communal life goals and alternative means to social integration need to be considered.

But how might this be operationalised? A desire for social support was a theme that emerged repeatedly from the participants’ narratives. The common conceptualisation of social support has included two functions (Schaefer, Coyne, & Lazarus, 1981). The first is practical, tangible or instrumental support. This incorporates the use of social relationships to achieve a goal, including the use of reciprocal interpersonal relationships to provide access to resources. The second function is emotional or expressive support and refers to the affective aspects of relationships. Examples of support in this context include sharing emotional problems, exchanging life stories or sharing a meal. Frequently problems with affective functions of social support are suggestive of a lack of strong-tie friendships (Douglas & Spellacy, 2000). Relationships that function at the level of emotional support attribute respect and value to an individual (Johnson, Douglas, Bigby, & Iacono, 2012). It has been suggested that people need strong-tie reciprocal relationships - people close to them with whom to share their feelings, problems, ideas and aspirations (Douglas & Spellacy, 2000).

Within the current research context, participants appeared to experience support primarily at the level of instrumental support (such as support with self-care tasks and physical activities) and expressed a desire for greater levels of affective support. They also articulated a desire for an increase in natural supports within the wider community in contrast to support only provided by the service provider. This was related to a recognition that emotional, affective or expressive support needed to be gained from outside the residential setting. The perceived lack of social linkage in the community was also coupled with a perception of fewer opportunities to build new reciprocal relationships. This was particularly evident for Simon who clearly articulated feelings of isolation and sense of a dissolving life.

Emerging from the data was also the strong sense that people wanted to contribute to others. They wanted to be a friend and not just have a friend. This appeared to be related to sense of purpose and meaning for the individual. An inability to contribute to others led to feelings of stagnation and of being a burden. Reciprocity is integral to supportive relationships, provides feelings of “competence, esteem and a sense of
belonging” (Heller, Price & Hogg as cited in Johnson et al., 2012, p. 324) and relates to the giving and receiving of social support. Douglas (2013) found that participants’ construction of their self-narrative was frequently associated with the setting of altruistic goals. Ware, Hopper, Tugenberg, Dickey and Fisher (2007) also found that social inclusion could contribute to, and enhance or develop, connectedness and citizenship. In a metasynthesis of qualitative studies Sarre et al. (2013) found that a limitation on the ability of an individual to provide support, or otherwise make a useful contribution through work or other activities, could be a source of anxiety and regret in people following a stroke.

So what is the impact of a lack of social connectedness? Research underlines the profound way we are affected by the social relationships we form with others, and by our social environment. “Social isolation can have devastating consequences with profound negative effects on resilience, health and wellbeing” (Jetten, Haslam, & Haslam, 2012a, p. 20). Being embedded in a social network provides real benefits for health and psychological wellbeing with a wealth of evidence demonstrating the positive impact of social connectedness in this regard (Haslam et al., 2008). Indeed, indices of social engagement appear to be significant and reliable indicators of psychological functioning, community integration, family functioning, life satisfaction and quality of life (Douglas, 2013). Importantly, social relationships have been found to make an contribution to health outcomes even after controlling for variables that are typically associated with adverse health (Jetten et al., 2012a). Jetten et al., (2012a) also report findings from a recent metaanalysis that demonstrated that the magnitude of the effect of social relationships on mortality is comparable to quitting smoking, and exceeds that for obesity, high blood pressure, and physical inactivity.

Within the TBI literature, Douglas and Spellacy (2000) found that social support, and particularly strong-tie emotional and affective support, was a significant and reliable indicator of depression for adults with TBI. Gracey et al. (2008) has also highlighted the role of social activity on the personal construction of self, with social interaction and engagement facilitating wellbeing and the dynamic construction of self-concept after a brain injury. Specifically, emotional wellbeing is underpinned by a person’s linkage to the social environment, including intimate and confiding relationships (Douglas, 2012). Conrad et al. (2010) and Doering, Conrad, Rief and Exner (2011)
have demonstrated that subjective wellbeing was strongly associated with the discrepancy between importance and success in the intimacy domain when exploring the relationship between life goals and subjective wellbeing. Kruithof, van Mierlo, Visser-Meily, Van Heughten and Post (2013) undertook a systematic review within the literature around outcomes following stroke, and found that social support was significantly associated with stroke survivors health-related quality of life. Emotional support (as opposed to informational, instrumental and appraisal types of support) showed the strongest relationship. However, the evidence for this is inconsistent at present due to the small number of studies, and the heterogeneity of the methods used to assess social support. Nevertheless the results from the systematic review undertaken by Kruithof et al. (2013) suggested that social support should be a substantial focus in acute and chronic rehabilitation programmes with an emphasis on the quality of interactions over the frequency of contacts.

There has been limited work to date exploring the effectiveness of interventions specifically targeting the development of social connectedness in people following TBI. Douglas, Dyson and Foreman (2006) found that becoming socially connected and involved in group-based community activities makes a difference to the emotional wellbeing of people following severe TBI. The intervention included people with TBI participating in community group programmes and promoted the use of leisure activities of their choice. This involvement aimed to develop natural social networks within communities. Activity programmes were facilitated by regional agencies who coordinated a calendar of activities offered within their own service or in the local communities. The activities offered were in line with the interests and preferences of the clients with brain injury. The agency also coordinated shared transportation. The amount of time spent in the activities ranged from one to six hours per week according to client preferences. Results from this study were supportive of health benefits of social activity but only if the involvement was sustained for more than six months. Specifically there was a significant increase in social integration and mental health, a significant reduction in depression and decreased reported problems with companionship. However, these positive results were only evidenced in a small sample of six people (out of the 25 people recruited) who had sustained activity for greater than six months. Nevertheless, this published research provides some limited
empirical support for the health benefits of social activity for people with severe brain injury.

Therefore, in summary, I suggest that the results from this current investigation are supportive of the maintenance or repair of subjectively perceived social connections and relationships being treated as one of the primary foci of rehabilitation rather than as a matter of only secondary concern (Conrad et al., 2010; Doering et al., 2011; Haslam et al., 2008; Sivaraman Nair & Wade, 2003b). This is also in contrast to relationships being viewed as merely a hopeful by-product of activity and participation. I posit that there is a need to break the cycle of diminishing social ties over the life span and help people following severe ABI to develop and maintain close-tie reciprocal friendships. A focus on increasing access to services and activities that offer opportunities for social, leisure and vocational participation outside of the residential context is also advocated. There is compelling evidence about the impact of social relationships on health, however a comprehensive and clearer picture of the interplay between social relationships and health is required (Jetten et al., 2012b) particularly in people with neurological disability. The development and validation of theoretical frameworks and clinical tools, aimed at encouraging and prompting social relationships after ABI, are also required.

It must also be acknowledged that social relationships are not easy to develop or sustain (Haslam, Jetten, & Haslam, 2012). Individually focused and flexible interventions are required to facilitate a sense of belonging and social identification in this client group. I contend that life goal planning, as a means of addressing people’s own preferences and personal meanings within the provision of rehabilitation, would ensure the specificity of the interventions and therefore maximise their chance for success.

5.3 Facilitators and barriers: balancing the wobble-board

Analysis of the interviews with participants suggests that in terms of attaining success in the relationship domain, the barriers and facilitators to the actualisation of life goals were viewed through the dynamic and complex interplay of both the participants’ milieu (as outlined in the theme ‘Opportunities arising’), and personal factors related
to self (as outlined in the theme ‘Unchanged, changed and changing’). My second key position within this discussion is that there is a need to keep a focus on the role of the environment in determining outcomes following an ABI and on the assumption that social environment is susceptible to change instead of viewing it as fixed.

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) recognises the importance of context in that it frames disability as a person-task-environmental interaction rather than something located solely within the individual. Participation, including participation in social encounters, is influenced by both personal and environmental factors. The participants in this investigation identified the importance of the social context that allowed opportunities for pursuit of life goals to arise. My previous assumption was that in this group, with severe on-going functional loss, it was frequently impairments and personal factors that prevented life goal achievement. However, in this specific context, within this sample, the participants’ milieu emerged as a key variable enabling or impeding life goal achievement.

Within this discussion I am referring to environment in its broadest sense, as is used within the ICF (WHO, 2001). I have therefore chosen to use the word milieu. Milieu conveys factors relating to both the physical and built space, as well as factors relating to the attitudes of others, and resources or opportunities within the environment (Jahiel & Scherer, 2010). Therefore, in this discussion, the term milieu describes the physical and social context in which people live, work and participate. For the participants in this investigation this milieu also included experiences specifically relating to organisational systems and processes, models of care, and staff support within the residential rehabilitation context. All of these factors were seen as either helping or hindering the participants’ ability to be part of things and to experience a sense of belonging.

Within the ICF, the conceptualisation of the environment allows for “identification of how the environment might contribute to health and disability, as well as how changes to specific environmental factors might impact on the experience of health” (Day, Theurer, Dykstra, & Doyle, 2012, p. 2). In a metasynthesis of the post-stroke qualitative literature, Reed, Wood, Harrington and Paterson (2012) found that the
The impact of stroke is influenced by interactions between the person, close social relationships and the social environment. This finding is reflective of other literature that has explored functioning following ABI (Levack et al., 2010; Muenchberger et al., 2008; Salter, Hellings, Foley, & Teasell, 2008). Reed et al. (2012) also posited that community-based support for people after a stroke would be most effective when delivered in the context of their unique social world. Participants within the current study all lived in a residential context, and the themes that emerged from the results provide some direction for how best to support people with severe impairments to achieve their life goals after an ABI within this specific context. Within this discussion I will focus on only some of the key emerging concepts relating to the participants’ milieu that emerged in the results: meaningful occupation and participation; the role of staff; and issues relating to agency, ethics and risk.

5.3.1 Meaningful occupation and participation

One key component of the context experienced by the participants related to the important role of occupation. Occupational roles provided participants with opportunities to develop relationships. They also provided mental stimulation, led to a feeling of being valued, increased participants’ motivation through a sense of contribution, and provided opportunities to be creative. Financial security was another environmental factor that contributed to the ability to achieve life goals. This is consistent with other research where a lack of money was found to increase distress for adults with TBI by preventing the pursuit of desired activities and in turn contributing to a sense of isolation and reduced social contacts (Douglas & Spellacy, 2000).

*Meaning* and *doing* are intrinsically linked in the process of reconstructing self-identity (Davis, Egan, Dubouloz, Kubina, & Kessler, 2013; Gracey et al., 2008; Klinger, 2005). Following brain injury, individuals make sense of themselves in terms of both subjective experience and activity together. This is because meanings are consolidated through activity in meaningful contexts. Ouellet, Morin and Lavoie (2009) provided additional support for the psychologically protective role of social activity. In their study TBI survivors who reported being active through work, studies or volunteering presented a significantly higher level of psychological adjustment than those persons
who reported no activity. Pierce and Hanks (2006) found that restriction of participation in life activities was found to be the ICF component that had the greatest impact on life satisfaction for people following TBI. “Self-story is developed and validated through social interactions and it is shaped continuously through ordinary and exceptional life experiences” (Douglas, 2013, p. 71)

**Participation** within the ICF is defined as involvement in a life situation and represents an observable performance within this life situation (Hammel et al., 2008). Participation is also closely aligned with the term *activity*. Activity relates to the execution of a task or action by an individual and represents the capacity to engage in a particular task (Hammel et al., 2008). Aspects relating to both activity and participation appear to connect to the term *occupation* within the current investigation findings. Assessment of participation can often focus on the individual’s performance as a primary and defining characteristic. However, there has been recent critique of this view, as it does not account for the role and supportive influence of social interdependence, or how embedded someone is in their community and support networks (Cardol, DeJong, & Ward, 2002). Instead of participation being solely determined by the ability to perform tasks by oneself, it is now also beginning to be conceptualised in relation to having access to resources and supports to participate fully (Hammel et al., 2008).

Hammel et al. (2008) conducted a qualitative multi-site study to gain an insider perspective from people with disabilities regarding the concept of participation. The research aimed to identify and describe meanings and indicators of participation, and the barriers and supports to participation. Several themes emerged across the focus groups: active and meaningful engagement / being a part of; choice and control; access and opportunity / enfranchisement; personal and societal responsibilities; having an impact and supporting others; and social connection, inclusion and membership. In this way participation was viewed as a complex and nuanced phenomenon that is person and context specific, with routes to the realisation of life goals being highly individualised. Participation was therefore viewed as an *expression of values* rather than as a set of activities. In addition, participation was also viewed as a means to experience social connectedness with other people and communities. The participants’ experiences in the current investigation aligned with the themes that emerged from
Hammel’s (2008) work. This supports the notion that participation in what is important in life can be viewed as a “dynamic process that involve[s] constant negotiation and balancing of competing needs and values across individual, social and societal levels” (Hammel et al., 2008, p. 1455).

But participation does not automatically lead to an increased sense of belonging. A sense of belonging is a perception that is unique to the individual centred on feelings of value, respect and fit (Mahar et al., 2013). It is not objectively determined and is separate from observable group membership. In a recently published paper, McLean, Jarus, Hubley and Jongbloed (2013) found that increasing the variety and frequency of social and leisure activities did not lead to an increase in subjective quality of life in people with moderate to severe TBI. Instead they found that increasing opportunities for people to participate with others was needed. They concluded that it was the subjective (as opposed to the objectively measured) nature of participation that is associated with positive influences on subjective quality of life in people with TBI. There is therefore a need to clearly delineate a subjective sense of belonging from objectively determined social participation. Physical integration does not necessarily mean social integration. As I have contended in relation to social relationships, ideally activities should be referenced to a person’s own preference and be shaped by their life goals and higher representations of self.

5.3.2 Role of staff

This section of the discussion highlights the effect of third party involvement on facilitating positive outcomes in terms of life goal achievement. It is important to consider and critique the nature of the therapeutic relationship within the residential setting (Ellis-Hill et al., 2008). It must be acknowledged that clinicians face competing objectives - the intent to provide care, support personal autonomy and maintain social connections and networks often needs to be balanced against the need to minimise the risk of harm to the individual (McColl et al., 1998). As an example, Simon’s coach facilitated his social encounters, but also held access to key resources such as taxi vouchers, so as to minimise risk.
Within the participants narratives there were a number of references to the facilitatory or gatekeeper roles that staff held. The availability or unavailability of staff to support participants to engage in activity towards life goal achievement was referenced. Feedback and validation from staff was also described as being important. Participants felt that achievement would be enhanced if there was encouragement and reinforcement for their accomplishments and efforts, and information suggesting progress.

The value attributed to life goal identification and attainment by staff working within the residential rehabilitation setting, also emerged as an important factor in determining whether life goals were actually achieved. Participants felt that sustained effort towards life goals required the support and affirmation of staff expressing faith in them. Participants felt that achievement was enhanced when there was encouragement and reinforcement for accomplishments and efforts, and information was provided suggesting progress. Gill, Wall and Simpson (2012) also found that a sense of self-belief was facilitated by interactions with staff. Some participants described a reluctance to share their life goals with staff as they felt that staff would not value their goals. A number of studies exploring outcomes after ABI have identified the perceived gap between the goals of the person and the rehabilitation professional (Holliday et al., 2007; Satink et al., 2013), and that professional aims may dominate over the aspirations of the person with ABI (Cott, Wiles, & Devitt, 2007; Levack, Dean, Siegert, & McPherson, 2011).

Facilitation and the encouragement of skill development by staff were also valued by the participants. Recognition and celebration of small and large successes contributed to a sense of validation and of hope. Such encouragement was seen as providing motivation for the participants. It appears that staff could develop and improve each person’s sense of wellbeing in their daily interactions with the participants via the facilitation of agency, competence and security (O'Sullivan, 2013).

The provision of appropriate levels of environmental and cognitive supports within a routine, and facilitation of the use of strategies towards task achievement, also contributed towards life goal attainment. However, there was a tension within this, as such support could be experienced by the participants as a loss of opportunity to be
spontaneous. Structures and processes that provided both flexibility and stability appeared to be valued. Bridget’s experience was supportive of this in that she did not consider that staff needed to provide one-on-one support for her, although she did recognise that staff had initiated, and maintained, strategies that allowed her to succeed in her life goals.

With respect to the participants’ desire for social connection, staff appeared to facilitate social encounters. This support was demonstrated in the initiation of activities, and in the provision of resources. Staff also held information on community opportunities. Douglas (2013) found that paid carers (in a community context) emerged alongside friends as facilitators of social connection. The participants in Douglas’ study described paid carers as people they could share their thoughts and feelings with. This finding is also supported by the work of Johnson et al. (2012). In adults with severe intellectual disability, affinity members who included family members and paid support workers, played an important role in facilitating positive relationships.

It is clear that staff provide support that can both facilitate, or hinder, the actualisation and achievement of life goals. However, this aspect of the rehabilitation environment requires more exploration to determine how best to facilitate positive outcomes for people with ABI who require residential support.

5.3.3 Agency, risk and ethics

Choice, control and ethics emerged from the interview data as inter-connected concepts that impacted on the participants’ ability to achieve their life goals. Participants expressed a desire for control over the little things in life and not just the big things. They wanted decisional and executional autonomy.

Firstly, agency emerged as an important concept for the participants. Within rehabilitation service provision there is a need to start with the goals and needs of the individual requiring the service (Cardol et al., 2002). The client is the key person to optimise the alignment between organisational and intervention decisions, and their life goals. This is in contrast to limiting service provision only to options available
within the service delivery agency or the funding model. Often environmental factors, such as models of care or organisational processes, are taken as given or fixed. This means that options offered to the clients are narrow. This lack of options represents de-facto disempowerment (Rapp & Goscha, 2012). Concepts related to self-determination require that people be given a full range of options from which to choose (Cardol et al., 2002). Participants within this investigation generally appeared to experience a limited range of choice – whether environmentally or cognitively derived.

It is acknowledged that participants within this study often did experience significant difficulties with decision-making. However, within rehabilitation services, valuing resident’s autonomy has been identified as being central to caregiving (Cardol et al., 2002; Tronto, 2010). Tronto (2010) has also argued that there are three elements of care required within an institution: power, plurality and purposiveness. Care institutions need explicit institutional arrangements to help resolve conflict between the intersections of these three elements as they arise. The best forms of institutional care will be those that are highly deliberate and explicit about how to best meet the needs of the people they serve. Magasi and Hammel (2009) undertook an ethnographical study exploring women with disabilities’ perceptions of living in a nursing home. They found that life in the nursing home was characterised by lost choice, control, and occupational engagement, social isolation and a loss of social control. McCormack, Karlsson, Dewing and Lerdal (2010) have also highlighted the significance of the care environment characteristics and care processes, on the enactment of person centred practice in people with long term health problems.

Decisions impact on a person’s way of life and have meanings attached to them (Cardol et al., 2002). Cardol et al. (2002) have also asserted that the more important an activity is to an individual, the more important it is to respect and facilitate autonomous decision-making around that task. That is, the right and recognition of decisional autonomy may be more important than the ability to perform activities by one’s self. However, people who have been in a dependent social position for some time, where their wishes have not been prominent, may lose sight of their own preferences (Rapp & Goscha, 2012). There is therefore a need to continually encourage participation in decision-making no matter how small, with support being
given for people to take charge of successively more important life choices. The concept of allowing people a number of choices from which to choose, links back to the importance of the generation of multiple alternative pathways to life goal attainment when considering goal adjustment and goal disengagement strategies - since the presence of options among which to choose is an inherent element of empowerment.

Secondly, **risk minimisation and management processes** were highlighted within the participant’s narratives. While such processes are implemented to minimise risk to an individual and organisation, this can lead to a loss of autonomous agency particularly in residential settings (Levack et al., 2010). An important consideration is: when do staff and organisational needs, around safety and risk minimisation, start to infringe on the rights of the person with ABI to autonomy? It is important to acknowledge the significant levels of anxiety that can be experienced by staff when supporting people with cognitive loss (Graham et al., 2013). However, staff paternalism and overly protective behaviour have also been shown to impact negatively on outcomes (Satink et al., 2013).

There is the recognition that the milieu of people in residential rehabilitation for ABI is always going to be a challenge in terms of achieving life goals. Risk management standards and processes exist for a reason. Importantly however, when making decisions around risk minimisation clinicians need to also consider the risk of *not* doing something. For example, in terms of social participation, processes may minimise the risk in one area (such as disorientation) but increase the secondary effects of social isolation and loss of social identity by limiting opportunities for social inclusion. This means that as clinicians and care staff, we need to develop a deeper understanding of the meaning of social identity and the importance of this construct for the person we are supporting. We can then feed more positively into on-going discussions around risk minimisation decision-making. This would more effectively contribute to supporting the individual to achieve their life goals, particularly around a sense of belonging, and more broadly into issues of social inclusion.

Thirdly, issues relating to **ethics** emerged within this research. I came to understand through the research process within this investigation, that if you do ask people with
severe ABI what is important to them, ethical issues will arise. If we take what people say seriously, then we will need to ask difficult questions about how we deliver services to them, while at the same time maximising their autonomy and supporting them to minimise their risk. One aspect of the clinical decision making process is whether we give full credence to the expressed desires and needs of people with cognitive disability. How much validity is attributed to the thoughts, desires and meanings of people with cognitive loss following ABI? There is a sense that a lack of attention can be given to the experiences, perceptions and feelings of people with cognitive disabilities. Often what we see as clinicians (our objective assessments) is privileged over what the person with cognitive impairment will say (their subjectively reported experience). This results in a prioritisation and promotion of professional assessment and objective understandings, over client understandings and experiences (Barnard, Cruice, & Playford, 2010; Brown et al., In Press; Levack et al., 2011). There is a need to explore the ethical and risk management implications together with clients to allow for a “partnership towards autonomy” (Hunt & Ells, 2011, p. 967). Rehabilitation teams need to foster an environment where discussions about the beliefs and values of both the person with ABI, and those of the clinicians, are encouraged. This is to provide a method for collegial support while at the same time optimising autonomous decision making for the client (Knox, Douglas, & Bigby, 2013). I posit that ensuring an open dialogue within the rehabilitation team and on-going critique of decision-making processes, along with reviews of decisional outcomes, is a requirement of a rehabilitation service seeking to deliver person-centred care.

5.3.4 Summary and recommendations relating to the milieu

Overall I posit that there is a need to explore our assumptions about the susceptibility of the physical, social and organisational environment to change. There is a risk, when considering the lives of people with ABI, of assuming that environmental factors are fixed. This can mean that the options offered to clients can be narrow. Attention should be given to thinking creatively about social environmental barriers and facilitators that allow (or prevent) people with cognitive issues to access their environment as easily as possible. Efforts should be made to overcome these difficulties and to support individuals to make decisions for themselves. Rehabilitation
should be aimed at addressing obstacles to inclusion rather than only illness-related impairments, and clinicians should constantly challenge the identification of causes of poor outcome at only an individual level. “Recovery should move away from disease and deficits and move us toward human potential and wellbeing. It should move us out into the community rather than withdrawing from it, seeing possibilities rather than only barriers. A focus on personal recovery should enhance the uniqueness of each person before us” (Rapp & Goscha, 2012, p. 14).

Hart and Evans (2006) and Sivaraman Nair (2003) have suggested that the effective use of cognitive and behavioural strategies are required for a person to achieve their goals. Through data analysis and reflection upon the experiences of the participants in this study, I would argue that the role of environmental factors in terms of goal attainment is not given enough consideration within the long term rehabilitation and support of people with ABI. If we are to effectively assist people with ABI to experience success in life goal attainment, then we will need to consider more specifically the role of environmental factors in rehabilitation outcomes and in the person’s subjective wellbeing. Ellis-Hill et al. (2008) posited that there has been limited appreciation of the social and psychological processes that underpin rehabilitation. This position appears to be consistent with the experiences of the participants in this study.

O’Sullivan (2013) has provided an overview of an effective, and arguably more ethical, approach to residential care for people with dementia. The combination of intervention strategies included changing staff perceptions, staff training, person-centred care, an occupational perspective and changes to the physical environment. Such a multi-faceted approach to environmental change takes into consideration the ways that living environments can be structured so as to facilitate autonomous functioning. Gibson et al. (2012) undertook an analysis of what constitutes an adequate home environment for adults with significant mobility disabilities. The term home environment referred to “relational spaces constituted through the mutually reinforcing and reciprocal relationship between people and place” (p. 2). They found that an adequate home environment is one that enables and promotes social dignity by providing access to seven essential conditions: self-expression; safety and security; meaningful relationships; community and civic life; participation in school, work or
leisure; respectful care relationships; and control and flexibility. While this research was undertaken with a group of people living in a range of community housing and continuing care units, the threshold conditions are resonant of the experiences of the participants in the current investigation.

Within the current study it is interesting to compare the experience of Bridget who lived in the Active Support cottage, with other people while lived in the larger facility. One is not able to make generalisations based on this study alone, however Bridget’s narrative would suggest that being in the smaller living environment, with an alternate model of care in place, may have better supported her to achieve her life goals. An alternate explanation may be that Bridget was selected to live in the Active Support cottage because of her greater cognitive capacity, although such an assessment of capacity was not explicitly considered as people were being selected for placement. Nevertheless, research into outcomes of people living in homes utilising the Active Support model of care echoed Bridget’s experiences. Literature around the implementation of Active Support have reported more positive relationships with staff and a greater range of activities being offered to people with intellectual disabilities (Jones et al., 2001; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Stancliffe et al., 2008). Graham et al. (2013) undertook research into the implementation of Active Support in the clinical context that the current investigation was undertaken, and found that the adoption of Active Support led to more normal and satisfying lives for the clients. They reported that there was also a clearer understanding of caregiving values including greater power sharing. The enactment of enabling and empowering values was demonstrated, and the stakeholders also experienced greater social connectedness. Therefore further consideration of the options that alternative models of care may provide for facilitating the achievement of life goals, including social connectedness and belonging, may be required in residential rehabilitation services.

The Strengths Based Model (Rapp & Goscha, 2012) has emerged from the field of mental health, but it is relevant to people with long term complex impairments. Within the mental health strength based literature, is the concept of an enabling niche. A niche attends to both individual and environmental factors and can be defined as entrapping or enabling. The concept of a niche encourages clinicians to think beyond
social location to social relations and recognises that people may be in the community (social location) but still not of the community (social relations). The creative element of environmental facilitation is encapsulated within the concept of an enabling niche in that clinicians are encouraged to focus on “finding, cobbling together or creating enabling niches” (Rapp & Goscha, 2012, p. 37) as a focus for their interventions. A key proposition of the Strengths Based Model is that the quality of the niches people inhabit determines their achievement, quality of life, and success in living. It would therefore be worth considering how the concept of the enabling niche could be adapted to use with the long-term rehabilitation needs of people with severe ABI.

In summary, one must consider the role that the environment plays in facilitating, obstructing or transforming participation given the dynamic interplay between the person and the environment (Hammel et al., 2008). Emerging from the results is evidence that the organisational policies and procedures, staff interaction, and issues related to agency and risk, all had an impact on the physical and psychological functioning of the participants and impacted on the achievement of their life goals. “Successful goal attainment is frequently the product of a complimentary match between the goal and the environment. Goal attainment may fail if the necessary resources are not available, accessible or accommodating” (Rapp & Goscha, 2012, p. 137).

5.3.5 Intra-personal factors

Environmental issues were not the only factors that emerged from the participants’ narratives as facilitators or barriers to life goal pursuit. The on-going impact of impairments also had an influence on the identification and actualisation of life goals for the participants in this investigation. While hope, self-efficacy, self-management skills and strategies also emerged, I would like to briefly focus on two issues in this discussion: memory and awareness

Life goal literature has referenced the impact of memory and cognition on life goal identification and achievement (Evans, 2011; Sivaraman Nair, 2003; Sivaraman Nair & Wade, 2003b). However, I was surprised by the clarity with which the participants could express their life goals and by their ability to describe their experience of what
was important to them, even if they had difficulty articulating what their daily goals and tasks were. Who they were as a person was coherently expressed, despite an inability to necessarily articulate a short-term goal or activity that was meaningful to them at that present moment. That is, the participants’ understanding of their essential self appeared to be more coherent than their memory of day-to-day events. Autobiographical memory has semantic and episodic components both of which support identity formation. Rathbone, Moulin and Conway (2009) have demonstrated that it is possible for individuals with severe episodic memory loss to maintain a sense of self based solely on semantic memory, although the experience of this sense of self may be qualitatively different. The participants’ experiences in this study support the notion that, even for those with severe memory impairments, life is purposeful and life goals can be articulated and discussed. Participants were able to talk about their desire for activities that could be linked to higher order meanings and identity, even if they were not able to clearly articulate specific short-term goals.

Deficits in self-awareness are thought to impact on rehabilitation outcomes and wellbeing (Prigatano, 2005). “Given the role of subjective processing in shaping outcome following TBI, self awareness is likely to contribute to the development of an individuals’ sense of self and emotional wellbeing” (Douglas, 2013, p. 70). However, I would argue that in the context of life goal assessment and planning, the level of a person’s self-awareness is not so relevant. Self-concept is a personal cognitive scheme constructed through subjective processing of the experience with his or her social world. Whether there is accuracy of self-appraisal in relation to another’s perspective does not impact on what the person perceives to be important. Also it should be noted that within a constructivist approach the existence of multiple subjective realities, rather than one single reality, is readily embraced. Nevertheless, participants may not be able to make a coherent link between being able to articulate life goals verbally and taking action towards the achievement of life goals. This may be due to difficulties in initiation or an inability to strategize or break down higher representations of self into realistic steps.
5.4 Clinical implications and recommendations

As I have argued, rehabilitation services should consider the role of social identity and broader environmental barriers and facilitators in supporting people to achieve their life goals after a brain injury. This research has added the voice of the person with ABI to the body of life goal literature. I have posited that rehabilitation services should constantly and explicitly seek the perspectives of end users (EU) in terms of their personal desires, meanings and aspirations in the provision of rehabilitation services. The exploration of concepts relating to life goals is paramount for ensuring that the perspectives and understandings of people with complex ABI primarily dictate the direction and scope of services provided to them, thereby enacting the objective of person-centred practice. EU should be directors of the process since they have the right to define their own life experiences. I will therefore make three recommendations for clinical practice: open dialogue between the person with ABI and the professionals; the facilitation of a coherency between day-to-day activities and life goals; and consideration of the temporal aspects of living with an ABI.

Firstly the enactment of person-centred care requires regular, in depth and open discussions about life goals. There should be a dialogue in which the individual’s values, life goals and preferences are discovered (Bright, Boland, Rutherford, Kayes, & McPherson, 2012; Cardol et al., 2002; Ward, 2012). I propose that as clinicians we need to ask how questions rather than what questions. We have been asking what is rehabilitation. What do you want from your life? What is important to you? But there is a need to ask how questions. How do you want to live your life? How can rehabilitation lead to person-centred and meaningful outcomes for you? The how question is the interrogator of direction, of doing, of curiosity, of process, of learning, and of living. When we ask how, we are not asking for a fact, conclusion, or opinion. Rather we are seeking a hands-on deeper knowledge of the ‘thing’. Often clinicians want a specific plan of action – a plan that attends to the what question. In terms of goal planning clinicians may benefit from asking how questions that draw on the personal meaning attributed to the functional goal set by the client. This could include how the activity reinforces who they are and how it helps them feel part of things.
Secondly, the enactment of person-centred care will require a focus on the **coherence between daily activities and the person’s life goals**. The participants’ experiences supported the need for explicit and documented linking of specific therapeutic activities to life goals, and not just strategies for the retention of day-to-day task recall. Strategies, and technological interventions, that support the integration of experiences into personal and social identity and higher representations of self are also required (Doering et al., 2011; Evans, 2011). Consideration should be given to the specific impairments that restrict the individual’s ability to internalise their experiences into a coherent and positive sense of self (Gracey & Ownsworth, 2012). Confusion and reduced sense of subjective wellbeing may occur when the person’s monitoring process is disrupted because of misinformation or cognitive problems (McGrath & Adams, 1999). Specific strategies that may be required to support a positive view of self in the light of life goal attainment could include: providing ways to remind people what they think is important on a day-to-day basis; helping them to recall ways that they have contributed; and implementing strategies to assist them in assessing their progress and rate of progress towards goal achievement.

One systematic process that may be useful in assisting with life goal achievement in this population is Metaphoric Identity Mapping. Ylvisaker and colleagues (Ylvisaker, McPherson, Kayes, & Pellett, 2008) have described and advocated a focus on identity by linking meaning, goals and tasks. Metaphoric Identity Mapping is used to help individuals to set personal goals that are consistent with a sense of identity that is valued by the individual. Metaphors (often an admired person) are used to capture the essential elements of the desired identity, and then steps are taken to specifically link lower order tasks (concrete goals) with higher order representations of self (life goals). Early evidence from pilot studies are suggestive of the acceptability of this approach to clients, although there was a mixed response from clinicians due to their perception of the approach being at odds with their clinical skills and role. Use of an everyday metaphor such as a hero figure can be an effective way to converse about complex, abstract ideas with people who have brain injury, and it can possibly facilitate a different type of engagement in rehabilitation programmes to the benefit of those individuals (McPherson, Kayes, & Weatherall, 2009; Ylvisaker et al., 2008). Metaphoric identity mapping therefore represents a pragmatic way of incorporating self-identity, and arguably life goals and higher representations of self, into
rehabilitation interventions as a central component. In summary, I would concur with Muenchberger et al. (2008) who stated that “this client focused and value driven approach to rehabilitation practice involves creating a dynamic and flexible context in which individuals can move forward and expand their opportunities in ways not necessarily concordant with established outcome indicators and social expectations” (p. 991). Such a flexible context should include strategies to explicitly link day-to-day activities with higher representations of self.

Thirdly, I propose that the enactment of person-centred care will require considering how life goals for individual people change or are re-prioritised over time. There is increasing evidence that ABI should be considered a chronic health condition, and as a disease process rather than a one-off event (Corrigan & Hammond, 2013; Masel & DeWitt, 2010). Rehabilitation services should therefore consider the longer term needs of the person with a severe brain injury rather than primarily focusing on the restoration of function immediately after the injuring event. Rehabilitation has tended to prioritise the treatment and recovery of impairments, independence and skills acquisition over interdependence and growth of self through life goal attainment (Kuenemund et al., 2013). Services tend to offer clients with ABI a treatment approach over the life span – rather than strategies to live well in the long term. There is therefore the need to consider how systems of support can be facilitated, along with different ways of adjusting and modifying these supports as people and their circumstances change.

The results from this research have challenged my own practice. I have tended to view cognition and memory impairments, along with physical recovery, as eventually plateauing. This has led me to think about the person with ABI at the residential stage of rehabilitation as being essentially static, with on-going rehabilitation input then being aimed at maintaining the person at their optimal levels of functioning. But the participants’ experiences expressed in this study reflected growth, personal development and new expressions of self rather than maintenance or stasis. Self-conceptualisation has been shown to be dynamic and cyclical in nature (Douglas, 2013; Muenchberger et al., 2008). There are a number of models incorporating a focus on growth and the restructuring on self-representations. Brandstadter and Rothermund’s (2002) dual process framework posits that stability and personal
continuity, as well as adaptive flexibility over the life span, are dependent on the interplay between assimilative tenacity (goal enhancement) and accommodative flexibility (goal disengagement and reengagement) processes. Brands, Wade, Stapert and van Heughten (2012) have also developed a model that focuses on goals, their pursuit and their revision - as a way of understanding adaptation over the longer term. Both of these models suggest that no final point of adaptation or resolution is gained. Rather, resonant with the wobble-board graphic, there is only a sense of tentative balance (see Figure 4.1). This relates to the on-going change seen within the theme ‘Unchanged, changed and changing’. The experiences of the participants within this research support the notion that reprioritisation processes do not appear to happen automatically and on-going interventions are required (Kuenemund et al., 2013).

Nevertheless broader questions have also emerged. There are potential threats to the ideals I am proposing within commercially driven rehabilitation frameworks. Baum (2011) has argued that there is a need to think of rehabilitation “as a continuum that is central to filling the gap between biomedical and population science and the gap between the biomedical system … and the broader sociocultural system in which people live” (p.169). Therefore I suggest that we also need to ask if life goals are part of the remit of rehabilitation as it is currently funded and provided within the New Zealand healthcare system. I would contend that this investigation has raised questions around the possible need for transformation of how we contract and provide rehabilitation services for this group of people. Are we resourced and structured to provide this kind of existential and long-term support? Should we even be calling the support around people in the long term after injury rehabilitation? Does someone undergo rehabilitation over his or her entire life span or would other types of community services better provide this support?

5.5 Future research

There is a need for further research to validate what are the most important outcomes for service users so as to improve the lives of people with disability (Bickenbach, 2011). Creative methodologies should be used to ensure the voices of people with severe ABI are heard within the literature, thereby informing the development of clinical practice. I would also suggest that the exploration of the position adopted in
this discussion using mixed methods, participatory action research or longitudinal designs would be helpful in developing deeper understandings of the needs and desires of people with cognitive loss following ABI. A qualitative meta-analysis of literature in the field of social connectedness and a sense of belonging in people with ABI would be beneficial to inform and enhance future research, clinical practice and support the work of advocacy groups. The Rivermead Life Goals Questionnaire (RLGQ) is posited to be a more suitable assessment tool for people with cognitive impairments due to its ability to assess life goals in a more concrete form (Sivaraman Nair, 2003). However, in this sample group I found it easier to explore more abstract representations of self throughout the interviews.

5.6 Limitations of research

The presence of significant memory impairments within this sample group, along with a lack of explicit life goal planning processes used at the residential facility, means that comment cannot be made on whether or not life goal planning actually happened for this sample. However, this investigation does explore its potential clinical utility within this population and explores factors that could influence life goal achievement. Also, specific comment cannot be made about the potential reduction in the significance of unattainable goals and development of new goals for the participants within the current methodology. Memory impairments have also contributed to the difficulty in understanding the participant’s experiences of this. It would have been interesting to have completed multiple interviews with the same participants to explore this issue further (Flowers, 2008).

This participant sample did perceive an explicit emphasis on life goals as being important, relevant, acceptable, and within the scope of rehabilitation services. The experiences of the participants also explored the role of rehabilitation professionals in goal planning around life goals. However a number of specific questions remain and require further research. Firstly, should life goal assessment be used to only inform goal setting at lower order level, or should they be used as the basis for explicit higher order goals? Secondly, at what stage do these concepts become important in the career of disability? Longitudinal research investigating whether life goal catagories and
attributes are changed following an ABI, and the impact that a loss or change in physical or cognitive functioning has on life goal attainment, is still required.

Throughout this research specific attention was directed towards sensitivity to context, rigour, and commitment to an ideographic approach. Horizontal generalisability in terms of either population or probability cannot be suggested from this research. Instead this study describes five people’s experiences in great depth. However, vertical generalisability was sought in terms of the ability to enhance understanding, enlarge insight and contribute to the body of evidence (Cassidy, Reynolds, Naylor, & Souza, 2011). Attention was directed toward an experiential account of significance to the participants, to interpretative as well as hermeneutic analysis, and caution was made in moving towards general claims. One criticism of IPA is that it relies too heavily on the participant’s ability to express him or herself (Brocki and Weardon 2005). However, as mentioned previously, I was surprised by the participant’s ability to do this. My experience of engaging in IPA included gaining a greater appreciation of the participants’ abilities to express themselves. IPA has also often been seen as being simply descriptive and lacking of rigour, with the subtlety and complexity of phenomenology’s aims and origins aims often being overlooked (Larkin et al., 2006). I therefore made transparent attempts to add to the interpretive depth of the analysis. As part of the data analysis, I completed an extra idiographically focused stage – that is, focusing on the particular nature of the participants narratives by writing up each person’s results in response to the emerging themes. The final themes presented within the results were not selected only on the basis of prevalence. Articulacy, immediacy and the manner in which the theme assisted in other aspects of the account were also considered (Brocki & Wearden, 2006).

Issues relating to my professional status also need to be acknowledged. The effect of power dynamics (Conneeley, 2002), the way the respondents placed me in the research process, the information they chose to give in the interviews and my subsequent interpretation of the data was influenced by my dual status as researcher and clinician. My clinical knowledge of the participants did have an influence on the interviews in that a rapport was quickly developed and participants appeared to be comfortable in sharing at a deep level. Participants also assumed that I was familiar with their life story and the residential context that was part of their experience. Often this required
me to ask them to tell me information that they assumed I already knew so as to ensure that my, and their, assumptions were concordant. However, I would also argue that this insider status added a richness and depth to the analysis and allowed for deeper interpretation of the results - the co-construction of outcome between the researcher and the person being researched. As outlined in the methods chapter, there was a need to continually attempt to bracket any perceptions arising and critically review the thought processes involved in the analysis of data. Nevertheless IPA as a methodology will always be inductive and provisional rather than absolute and definitive, since it is not possible to completely escape the contextual basis of my own experience.

5.7 Final summary

The principal aim of this research was not to understand what life goals are. Instead I sought to use the participants’ accounts to reflect upon life goals from the perspective of the participants’ engagement with them. Within this discussion I have argued that the life goals of people with severe ABI need to be considered more explicitly within person-centred rehabilitation service provision. Specifically a focus on the social identity of the person with ABI, along with greater attention to their changing milieu, is required.

We use terms such as person-centredness frequently in rehabilitation, but person-centred practice is not well operationalised (Bright et al., 2012; Gzil et al., 2007; Playford et al., 2000; Rosewilliam et al., 2011). Based on the experiences of participants within this study I posit that person-centredness recognises the EU’s right to identify and establish their own therapeutic and clinical goals based on informed choice, importance and satisfaction (Hammel 2008 p 1447). Life goal planning is one way of operationalising person-centred care in the rehabilitation context. It allows EU’s to direct their goals, to inform service delivery agencies on the importance attributed to their goals, and to articulate levels of satisfaction with their ability to achieve their goals. Life goal planning values the subjective experiences of the person with an ABI and allows a central focus on the needs and desires of the person with an ABI to be retained within service delivery models and frameworks. Finally, life goal planning allows for specific activities to be facilitated - activities which provide meaning for that particular individual. That is, when we start a conversation with
people about their life goals, we are much more likely to support a link to subjectively determined activities that are meaningful for the person with ABI. This investigation has therefore provoked ongoing thought and discussion around what person-centred care means, and the place that life goals may play in enacting this notion within a residential rehabilitation context.

Based on existing published literature, along with the findings of this investigation, potential options to promote the utility of life goal identification and achievement in the clinical environment include: regular, in depth and open discussions in which individuals values and preferences are discovered; a focus on the facilitation of coherence between daily activities and the person’s life goals; and consideration to the changes in what life goals are important to the person over time. Further research is needed to explore how rehabilitation and other community services can be best structured to enhance the lives of people with severe ABI.
6 References


Appendix 1: Rivermead Life Goals Questionnaire (RLGQ)

Various aspects and areas of life are given below. I would like you to tell me how important each is to you. Please rate the importance of each: 0 = of no importance, 1 = of some importance, 2 = of great importance and 3 = of extreme importance.

1) My residential and domestic arrangements (where I live and who with) are:
2) My ability to manage my personal care (dressing, toilet, washing) is:
3) My leisure, hobbies and interests including pets are:
4) My work, paid or unpaid is:
5) My relationship with my partner (or my wish to have one) is:
6) My family life (including with those not living at home) is:
7) My contacts with friends, neighbours and acquaintances are:
8) My religion or life philosophy is:
9) My financial status is:

Source:
Appendix 2: Life goals questionnaire (GOALS)

Source:
English translation from author (personal correspondence)

GOALS description
The questionnaire GOALS (Pöhlmann & Brunstein, 1997) assesses general, long-term life goals. Respondents are presented 24 goals pertaining to six major life domains: intimacy (close relationships based on mutual trust and affection), affiliation (spending time with other people, common activities), altruism (acting for the welfare of others), power (asserting oneself, seeking social status), achievement (improving on one’s self, meeting standards), and variation (seeking new experiences and excitement).

For each goal, three attributes are rated: importance (How important is it for you to reach this goal in your lifetime?), attainability (How good do you think your chances are to reach this goal in your lifetime?), and degree of success at attainment (How successful are you currently in attaining this goal?). Each of these three goal attributes is rated on a 5-point scale ranging from 1 (not important / low chances / hardly successful) to 5 (very important / high chances / very successful). Importance ratings indicate which goals are desirable and valuable for the person and indicate the strength of his/her commitment to a goal. Attainability ratings reflect the person’s outlook concerning how attainable a goal currently is or will be in the long-term based on his/her own efforts as well as on available resources and environmental affordances. The goal attribute success reflects the person’s current progress in attaining his/her goals.

On the following pages you will find a list of goals people want to reach in their lives.

Please tell us
- how important it is for you to reach this goal in your life
- how easy or difficult it is to attain this goal at the moment
- how successful you are at the moment in attaining this goal

For each of the goals mentioned mark a number between 1 and 5 on the respective scale. Please work on all statements swiftly but carefully and do not stick too long to single sentences.
Please mark for each goal how **important** it is for you to reach this goal in your life.

1-------2-------3-------4-------5

not important       very important

Importance

*I would like to*

1. improve my education continuously. 1----2----3----4----5
2. spend a lot of time with other people. 1----2----3----4----5
3. lead an exciting life. 1----2----3----4----5
4. support other people's causes. 1----2----3----4----5
5. be able to exert influence. 1----2----3----4----5
6. have a close relationship. 1----2----3----4----5
7. broaden my horizons. 1----2----3----4----5
8. be friends with many people. 1----2----3----4----5
9. live a life of adventure. 1----2----3----4----5
10. act unselfishly. 1----2----3----4----5
11. have a high social status. 1----2----3----4----5
12. give affection and love. 1----2----3----4----5
13. continuously improve myself. 1----2----3----4----5
14. engage in a lot of activities with other people. 1----2----3----4----5
15. enjoy life to the full. 1----2----3----4----5
16. do good. 1----2----3----4----5
17. gain public recognition. 1----2----3----4----5
18. have trusting relationships with other people. 1----2----3----4----5
19. to develop my skills. 1----2----3----4----5
20. have a wide circle of acquaintances. 1----2----3----4----5
21. lead an exciting life. 1----2----3----4----5
22. help other people who are in need. 1----2----3----4----5
23. have prestigious positions. 1----2----3----4----5
24. receive affection and love. 1----2----3----4----5
Please mark for each goal **how attainable** this goal is for you **at the moment**.

<table>
<thead>
<tr>
<th>1--2--3--4--5</th>
<th>very difficult</th>
<th>very easy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>to attain</td>
<td>to attain</td>
</tr>
</tbody>
</table>

**Attainability**

_I would like to_

1. broaden my horizons.  
2. be friends with many people.  
3. enjoy life to the full.  
4. do good.  
5. have prestigious positions.  
6. receive affection and love.  
7. develop my skills.  
8. engage in a lot of activities with other people.  
9. lead an exciting life.  
10. help other people who are in need.  
11. gain public recognition.  
12. have a close relationship.  
13. improve my education continuously.  
14. spend a lot of time with other people.  
15. live a life of adventure.  
16. act unselfishly.  
17. be able to exert influence.  
18. give affection and love.  
19. continuously improve myself.  
20. have a wide circle of acquaintances.  
21. lead a thrilling life.  
22. support other people's causes.  
23. have a high social status.  
24. have trusting relationships with other people.
Please mark for each goal how successful you are at the moment in realizing your goal.

1--------2--------3--------4--------5
not very
successful successful

Success

*I would like to*

1. develop my skills. 1----2----3----4----5
2. engage in a lot of activities with other people. 1----2----3----4----5
3. lead an exciting life. 1----2----3----4----5
4. help other people who are in need. 1----2----3----4----5
5. have a high social status. 1----2----3----4----5
6. have trusting relationships with other people. 1----2----3----4----5
7. continuously improve myself. 1----2----3----4----5
8. spend a lot of time with other people. 1----2----3----4----5
9. live a life of adventure. 1----2----3----4----5
10. do good. 1----2----3----4----5
11. gain public recognition. 1----2----3----4----5
12. receive affection and love. 1----2----3----4----5
13. broaden my horizons. 1----2----3----4----5
14. have a wide circle of acquaintances. 1----2----3----4----5
15. lead a thrilling life. 1----2----3----4----5
16. support other people's causes. 1----2----3----4----5
17. have prestigious positions. 1----2----3----4----5
18. have a close relationship. 1----2----3----4----5
19. improve my education continuously. 1----2----3----4----5
20. be friends with many people. 1----2----3----4----5
21. enjoy life to the full. 1----2----3----4----5
22. act unselfishly. 1----2----3----4----5
23. be able to exert influence. 1----2----3----4----5
24. give affection and love. 1----2----3----4----5
Appendix 3: Participant information sheet

An invitation
You are invited to take part in a research study to explore peoples’ thoughts and experiences of how setting goals in rehabilitation relates to what is important to you in life.
The purpose of this information sheet is to give you the information you need to be able to decide whether or not to take part in this research study. Please take it away with you to read and consider before making up your mind. You can contact Rachelle Martin at any time by phone or email to discuss the information, or to arrange a meeting.

Do I have to take part?
No. Your participation is entirely voluntary (your choice). You do not have to take part in this study.
If you choose not to take part, any care or treatment that you are currently receiving will not be affected.
If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason. Withdrawing at any time will in no way affect your future health care.

Who is running this study?
This study is being carried out by Rachelle Martin as part of the Masters in Health Science degree through the University of Otago. Her contact details, and the names and contact details of her supervisors, are provided at the end of this information sheet.
Rachelle also works as a physiotherapist at the [residential facility] and may be involved in setting up, reviewing or coordinating your rehabilitation programme. If, at any time you have concerns, you can ask for another therapist to replace Rachelle in her clinical role, or you may choose to withdraw from the study.

What is the aim of this research?
The aim of this research is to establish a better understanding of how people who have had a neurological injury set goals, particularly around what you want to do with your life. The research is also trying to understand how this could help rehabilitation professionals provide more effective and meaningful rehabilitation programmes and services.

Why do we want to do this research?
There is some evidence that talking to people about what is important to them in their life helps them to more effectively set realistic and useful shorter term rehabilitation goals.
In this study we want to explore the experience that people have of thinking about their ‘big life aims’ as they rehabilitate following a neurological injury or event. We want to use this information to improve the services provided to people undergoing rehabilitation.
Who can be in the study?
You are being invited to take part in this study because we feel that your experiences can contribute much to our understanding and knowledge of goal planning in rehabilitation.
You can be involved in this study:
- If you have had a neurological injury/event (e.g., stroke, traumatic brain injury, multiple sclerosis, brain tumors) more than one year ago
- If you are, either, still involved in rehabilitation, or have been in the previous two years
- If you are aged between 18 – 65 years
- If you are able to communicate with the researcher

For this study we wish to recruit approximately 6 people to be interviewed.

What happens if I decide to take part?
The study involves participating in one or two interviews with the researcher in the [residential facility], or another location convenient to you. It is expected that each interview will take around one hour to complete.
The researcher will arrange a suitable time to you. The interview will be audio recorded so we can be sure we have not missed any important details. This also means the researcher can focus on what you say during the interview rather than trying to take notes.
You can have a support person attend the interview if you choose, and you can stop the interview at any point you wish.

How long will the study run for?
The study will run from June to November 2012.

What will happen with the information from the study?
The recordings of the interview will be typed out, with all personally identifying information removed (such as names of people, places or organisations). The interview recording and all other information that you provide will remain strictly confidential. No material that could personally identify you will be used in any reports from this study. The researcher plans to write up the findings from this study for a variety of audiences. First, a report the participants (that means you and your family), second a feedback presentation to anyone interested at [residential facility], third a publication in a scientific journal and finally a presentation to a wider group of health professionals involved in rehabilitation. This is so that others may benefit from the study. You will receive a brief summary of the study findings if you would like.

How will the study affect me?
Taking part in this study will take some of your time and require you to talk about your thoughts and experiences. It is possible that some people may find talking about their experiences upsetting, but others may find this opportunity beneficial.
The results from this study and your participation may help other people in the future.
Your usual medical care or support will not be affected in any way by your participation in the study, or by declining to participate or withdrawing from the study at any stage. If the researcher is currently involved in your rehabilitation, you can ask for another therapist to be involved in your programme at any stage of the study.
Confidentiality
The information that you provide during this study will remain strictly confidential. No material that could personally identify you will be used in any reports from this study.
Upon completion of the study your records will be stored in a secure, locked cabinet at my home office. All computer records will be password protected. All future use of the information collected will be strictly controlled in accordance with the Privacy Act.

Your rights
If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Advocate at the Health Advocates Trust, Telephone 0800 555 050, or email: advocacy@hdc.org.nz

For more information
If you would like some more information about the study please feel free to contact:
Researcher: Rachelle Martin
Address: [residential facility]

Phone:
Email

Lead supervisor: Dr William Levack, Senior Lecturer in Rehabilitation
Address: Department of Medicine, University of Otago Wellington, PO Box 7343, Wellington 6424
Phone: 04 385 5541 x6279 or 021 918 627
Email: william.levack@otago.ac.nz

Supervisor: Anne Sinnott, Researcher
Address: Dept of Orthopaedic Surgery & Musculoskeletal Medicine: University of Otago, Christchurch
Phone: 03 431 2551 or 021 994 878
Email: anne.sinnott@otago.ac.nz

An application for ethical approval was made to the Upper South B Regional Ethics Committee. They stated that no ethics committee review was required for this research (ethics reference number URB/12/EXP/033). The [residential facility] Chief Executive Officer (CEO) and General Manager (GM) have reviewed this research proposal and given their consent for it to occur.

Please keep this brochure for your information.
Thank you for reading about this study
Appendix 4: Consent form

☐ I have read/had explained to me, and understand, the Information Sheet (Version 5, 14/6/12) for participants taking part in this study.

☐ I have had the opportunity to use family/whānau support or a friend to help me ask questions and understand the study.

☐ I understand that taking part in this study is voluntary (my choice), and that I may choose not to answer some questions or withdraw from the study at any time and this will in no way affect my future health care.

☐ I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.

☐ I understand that I can choose to have a support person present during my interview

☐ I have had time to consider whether to take part in the study

☐ I know who to contact if I have any questions about the study

☐ I consent to the interview being audio-recorded

I wish to receive a copy of the results. I understand that there may be a significant delay between data collection and the publication of the study results.  

Yes / No

I __________________________________________________________________________ hereby consent to take part in this research.

Signature ................................................................. Date

.................................................................

EPOA (if applicable).................................................................

Date:.................................................................

Project explained by .................................................. Project role ..............................................

Signature................................................................. Date

.................................................................

One copy of the consent form to be kept by the participant and a one copy to be kept by the Study Researcher
Appendix 5: Question guide

General introduction:
Brief explanation of project
Check ongoing consent, and reiterate their ability to withdraw this at any stage in the interview
Any questions?

Demographic data
Use data collection sheet & Barthel Index

Tell me about what has happened since your injury/event?
General outline of your story – pre injury/event, the event, since that time
Helpful or unhelpful elements/services

How have you coped?
How do you feel?
Can you tell me more about…?
So, what were the main stages/difficulties etc…?

What kind of life do you want to live?

What kind of person do you want to be?
Can you tell me a bit more about that?
What do you mean by…?

Who do you imagine yourself being?
Is one of these ‘most important things’ (we will call them life goals) more important than the other? If so which one (or two)?
Can you tell me more about why this life goal is more important?
Can you tell me why you think this is so important?
How do you feel about how ‘on track’ you think you are with achieving this life goal?
How satisfied are you with how on track you are? How much progress do you feel you are making?
Tell me more about how attainable/achievable these life goals are?
How has your disability affected your ability to achieve [add previously stated life goal]?

What do you think your life would be like if…?
Are you able to tell me what you think your family and friends think is the most important thing to you?
- Do you see yourself differently now than before you had your....?
- How do you think other people see you?
- How do you see yourself in the future?
- Have these life goals you have changed over time …over the ‘career’ of your disability?

To what degree have [life goals] featured in your rehabilitation?

How has rehabilitation contributed to your ability to achieve your [life goals]?
- What do you mean by…?
- How did that feel?
- Can you tell me more about…?
- Can you give me an example of…?
- Tell me about a time when you have adapted, given up, or changed the way you approached a life goal?
- What helps you to feel motivated to achieve [name the ‘life goals’ previously identified]?

Tell me more about whether it could be helpful, or not, to use your stated life goals to set rehabilitation goals around specific activities and/or tasks you want to improve at?
- Can you tell me about whether you would find it helpful to set some goals aimed directly at achieving [name the areas previously identified]?
- What are your thoughts about whether it makes a difference what stage your rehabilitation is at?
- Tell me more about what makes is hard, or easy to share your big life aims with rehabilitation therapists and staff?
Appendix 6: Prompt sheet

What kind of life do you want to live?

What things are most important to you in your life?

What kind of person do you want to be?

To what degree have life goals been a part of your rehabilitation?

How has rehabilitation contributed to your ability to achieve your life goals?
Appendix 7: Transcription conventions

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech. Ellipses (…) have been used to indicate where speech was omitted. Square brackets [ ] were used to insert editorial notes or words not present on the audiotape. Rounded brackets ( ) were used to indicate where nonverbal sounds such as laughter, or pauses occurred on tape.
Appendix 8: Health and Disability Ethics Committee

22 May 2012

Ms Rachelle Martin
5 Killie Street
Upper Riccarton
Christchurch
8041

Dear Ms Martin

Ethics ref: URB/12/EXP/033 (please quote in all correspondence)
Study title: The Experience of Life Goal Planning in the Rehabilitation of People with Acquired Neurological Disability: An Interpretative Phenomenological Analysis
Principal Investigator: Rachelle Martin

Thank you for the above application for expedited review which the Chairperson and Deputy Chairperson of the Upper South B Regional Ethics Committee have declined to review because under the Ethical Guidelines for Observational Studies: Observational Research, Audits and Related Activities, NEAC, December 2006, no ethics committee review is required.

Please note, however, that the organisation in which you wish to carry out the study may specify their own processes regarding notification or approval.

Yours sincerely

Diana T. Whipp

Mrs Diana Whipp
Upper South B Regional Ethics Committee
Email: Diana_Whipp@moh.govt.nz