Learning to live with an altered functional self after inpatient rehabilitation

by

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Declaration

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

Deidre Anne Widdall

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Key to Transcripts

When presenting excerpts from participant's interview transcripts in Chapter Three, the following conventions are used:

Shorter excerpts from participants are presented in double inverted commas in the text. Longer excerpts are indented and single spaced.

All participants are identified by a specific code. Participants are numbered, for example P1.

Excerpts from interview transcripts are identified using the participant's code number, a second number either 1 or 2 will identify if the excerpt comes from the first or the second interview and the transcript line number. For example, (P1.1, 200) indicates the excerpt comes from participant number one, first interview, and line number 200 at the commencement of the excerpt in the first interview transcript.

Square brackets [ ] are used to insert words to clarify meaning, for example, to give an explanation of what the participant was referring to, or where additional words were inserted. Parentheses ( ) are used to insert field notes into transcripts. To indicate that content from an interview transcript has been edited out, an ellipsis ...has been used.

Indigenous statement

In this document the term Indigenous is used and refers to Aboriginal or Torres Strait Islander peoples of Australia. Although used in this way, it is acknowledged that Aboriginal and Torres Strait Islander people are a culturally diverse group.

Abstract

Rehabilitation following severe and unexpected health events can require complex and multifaceted interventions. For the rehabilitation inpatient, leaving the inpatient unit after an often-prolonged hospital stay to return home and to usual life activities is an important and vital stage in recovery. Issues with providing a quality discharge experience and for continuum of care are well documented for the general ‘acute’ inpatient. There is a gap in understanding the perspectives of Australian individuals with a range of conditions after leaving inpatient rehabilitation to return to life in the community.

Using a qualitative descriptive design this study provides rich description of the lived experiences of persons who have a range of conditions resulting in impairment to body structure and functioning. Semi structured interviews were conducted with eight participants shortly after discharge and again within a few months to gain understanding of the experiences over time as the phenomena of interest was being experienced.

Data analysis revealed an over arching theme and three major themes containing further sub categories. The overall theme describes a learning process over time which participants engaged in where they were *‘Learning to live with an altered functional self’.* The three major themes depict and describe how participants experienced this learning and purposeful responses to changes in their health and functioning. The first theme, *‘Realising my functional self has changed’* involved discovering functional limitations for themselves and developing an understanding of the altered functional self. The second theme, *‘Taking charge to restore my functional self’* describes participants making plans to restore functioning and taking action to restore functioning. In the third theme *'Taking charge of my changed situation'* participants over time have come to an understanding of their changed situation and describe how they are living differently in the present with thinking of the future. Across all sub-themes important contextual elements of performing everyday activities, home and community were essential to learning, and adaptive processes. The study discusses the nature of these findings as they add knowledge from the person's perspective and within an Australian context. The implications for rehabilitation service delivery, educational preparation of health professionals and for future research are also explored.

Chapter One: Introduction to the study

Introduction

Discharge from hospital from a systems perspective incorporates the elements of quality patient care, continuity, efficient coordination, management of resources, availability of appropriate community discharge destinations and community support services (Health Board Executive, 2003). Efficient and timely hospital discharge enables access to available beds for those needing elective and emergency admissions. The ideal is for a whole systems approach that incorporates and enables all elements for admission and discharge to hospital, quality patient care, safety, satisfaction and service efficiency (Health Board Executive, 2003).

Guidelines for discharge support quality patient care elements, emphasising requirements for discharge planning as an integral part of routine health service care (Centre for Allied Health Evidence (CAHE), 2008; Queensland Health, 1998). Reports on hospital performance include data for a number of key areas of service usage and efficiency, including length of hospital stay, waiting times in Emergency Departments, waiting times for elective surgery, availability of hospital beds and others (Australian Institute of Health and Welfare (AIHW), 2013a; Australian Medical Association (AMA), 2013). Two approaches to discharge from hospital arise from these differing health service performance perspectives. These are a person centred and quality care approach to discharge, and a bed management/ patient flow approach.

The person centred and quality care approach emphasises the need for collaboration between the hospital and community sector, and has a commitment to high quality customer focused discharge planning. The health care needs of the patient, across the whole continuum of care, are acknowledged through an effective hospital - community communication system (Queensland Health 1998). Discharge from hospital is viewed as a process, not an isolated event, involving the development and implementation of a plan to facilitate the transfer of an individual from hospital to the alternative setting (The Health Board Executive, 2003). Discharge planning processes involve a multidisciplinary approach which facilitates each patient's continuity of care following an episode of hospitalisation, enabling better health outcomes, and reducing the likelihood of readmission to hospital (Queensland Health, 1998; Shepperd, Parkes, McClaran & Phillips, 2008). In Australia, the Australian Council on Healthcare Standards provides guidelines and clinical standards for quality of services and accreditation, which specifically address discharge requirements enabling continuum of care.

The bed management approach to discharge, (while acknowledging the importance of patient safety, continuity and accessibility of services), has a focus on organisational efficiency, patient flow, and efficient bed management (Proudlove, Gordon & Boaden, 2003; Boyer, 2002). Reduced length of hospital stay and better use of resources is the aim (Shepperd et al., 2008). Reducing waiting time and overcrowding in emergency departments is an important hospital performance indicator used to measure hospital efficiency and as such gains media attention, and is reported in the Australian Federal Parliament proceedings (Hansard, 2013). These matters are also of concern to the person waiting and to leading health professional groups (AMA, 2013).

Management of critical issues of discharge, patient flow and bed occupancy can involve a number of strategies/systems, for example: automated electronic systems for discharge processes and patient tracking (Boyer, 2002); bed management/operational capacity systems and procedures (Proudlove, Gordon & Boaden, 2003); bed management 'Toolkits' for clinical re-design (Victorian Government, 2005); and escalation procedures to increase throughput both for discharge and admission when emergency department occupancy is high (Harrison, Zeitz, Adams & Mackay, 2013).

A balance between the patient centred and bed management approaches to discharge is needed, where all elements support a streamlined patient journey, which is underpinned by best practice (The Health Board Executive, 2003).

The following sections will provide an overview of patterns of Australian general hospital usage, including the care type of rehabilitation, and more specific information about rehabilitation episodes of care comparing Australian patterns with the health service setting, the Royal Darwin Hospital, that was the location for this study. Literature about issues pertaining to discharge from hospital and life after rehabilitation is also reviewed.

Hospital separation statistics in Australia

In Australia, discharges are recorded under the broader classification of hospital separations. Separation refers to the end of an episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of care type (for example, from acute care to rehabilitation (Australian Institute of Health and

Welfare, 2013b). Both public and private hospitals provide hospital services. Public hospitals are owned and managed by state and territory governments, and mainly provide ‘acute care’ for short periods and some longer term care such as rehabilitation services (AIHW, 2013). Private hospitals are mainly owned and managed by private organisations, either for-profit companies or not-for-profit non-government organisations. They include day hospitals that provide services on a day-only basis, and hospitals that provide overnight care (AIHW, 2013). Majority of hospitals in Australia are public, as measured in figures from 2010, in which there were 753 57% public hospitals and 573 43% private, including day hospitals (AIHW, 2013).

Hospital usage patterns are reported and publicised yearly by the Australian Institute of Health and Welfare (AIHW). To enable understanding of the Australian hospital and health service context from a macro level some statistics from the most recent report available published in 2013 are provided. In Australia in 2011–12, there were almost 9.3 million admitted patient separations, 5.5 million in public hospitals and 3.7 million in private hospitals. Between 2007–08 and 2011–12 the number of separations increased on average by 3.8% each year for public hospitals, and by 4.6% for private hospitals (AIHW, 2013a, p. 8). Care types included acute, rehabilitation, palliative, psychogeriatirc, geriatric evaluation and management, maintenance and other (AIHW, 2013a). Average length of stay in 2011-12 (including same day separations) was 3.4 days for public hospitals and 2.3 days for private hospitals, with the overall average being 3.0 days (AIHW, 2013a).

Rehabilitation: Sub-acute care in Australia

Within the Australian health care system, rehabilitation is one type of ‘sub-acute care’, with the others being palliative care, geriatric evaluation and management, and psychogeriatric care. More specifically, rehabilitation care is “care in which the primary clinical purpose or treatment goal is improvement in the functioning of a patient with an impairment, activity limitation or participation restriction due to a health condition” (AIHW, 2013b, p. 9). The person needs to be capable of actively participating in, individualised, multidisciplinary planned care, delivered under the management of, or informed by, a clinician with specialised expertise in rehabilitation. The management plan includes negotiated goals within specified time frames and formal assessment of functional ability (AIHW, 2013b, p. 9-10). The reason for rehabilitation may relate to functioning of the whole body or a body part, the whole person, or the whole person in a social context, and to impairment of a body function or structure, activity limitation and/or participation restriction (AIHW, 2013b).

Data regarding rehabilitation care can be found in the hospital statistics reports for sub-acute care separations in Australian hospitals, and in reports from the Australasian Rehabilitation Outcomes Centre (AROC).

AROC collects and reports on a prescribed data set from member rehabilitation units for each and every episode of rehabilitation. The data set includes demographic information, measures of length of stay and changes in functional status measured using the Functional Independence Measurement (FIM) on admission and discharge. AROC also reports on the Australian Clinical Healthcare Standards (ACHS) rehabilitation medicine clinical indicators. This includes Clinical Indicator 4: Discharge Plan - establishing a discharge plan (AROC, 2013).

In the AIHW (2013b) hospital statistics report for 2010-2011, rehabilitation care represented the highest proportion of sub-acute care for both separations (75.6%) and patient days (57.6%). Rehabilitation care was the most common type of sub-acute care in both public (52.5%) and private sectors (93.2%) (AIHW, 2013b). In 2011, there were approximately 180 inpatient rehabilitation units in Australia, comprising 100 public sector and 80 private sector units (AIHW, 2013b).

Rehabilitation care type separations have been steadily increasing in recent years, with an average yearly increase of 12.2 % from 2007 to 2012 (AIHW, 2013a). There has been a larger increase in separations from the private rehabilitation sector (AIHW, 2013a) – see Table 1.

Table: 1 Rehabilitation separations, public and private hospitals, 2007–08 to 2011–12

	2007-2008	2011-2012	Average yearly % increase
Public hospital	75,446	95,562	6.1
Private hospital	115,659	226,887	18.3
Total	191,105	322,449	12.2

Overall, the average length of stay for sub-acute care is much higher than the average length of stay for acute care, and was higher in public than private hospitals. For example, in 2011-2012 the average length of stay for rehabilitation care was 17.0 days in public compared to 4.6 days in private hospitals. The total average length of stay for acute care of 2.9 days compares as much less than the average length of stay in public rehabilitation of 17 days (AIHW, 2013a) – see Table 2.

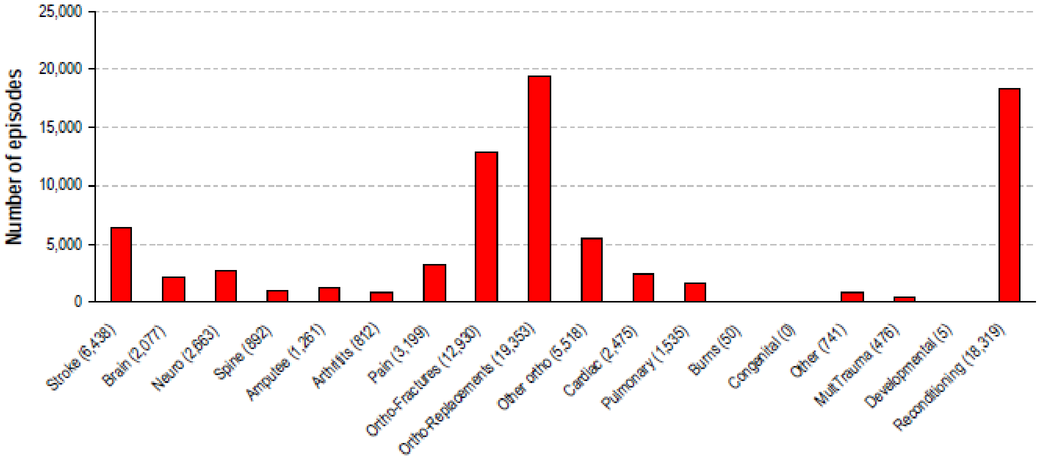
Table: 2 Rehabilitation compared with Acute care - Average length of stay (LOS) public & private hospitals, 2011–12 (includes same day separations)

	Public Hospitals	Private Hospitals
Rehabilitation LOS (days)	17.0	4.6
Acute care only LOS (days)	2.9	2.1

The AROC annual report on inpatient rehabilitation in Australia for 2011 reported continued growth and a 5% real increase in inpatient episodes of rehabilitation provided in 2011 since 2010, at member facilities (AROC, 2012a).

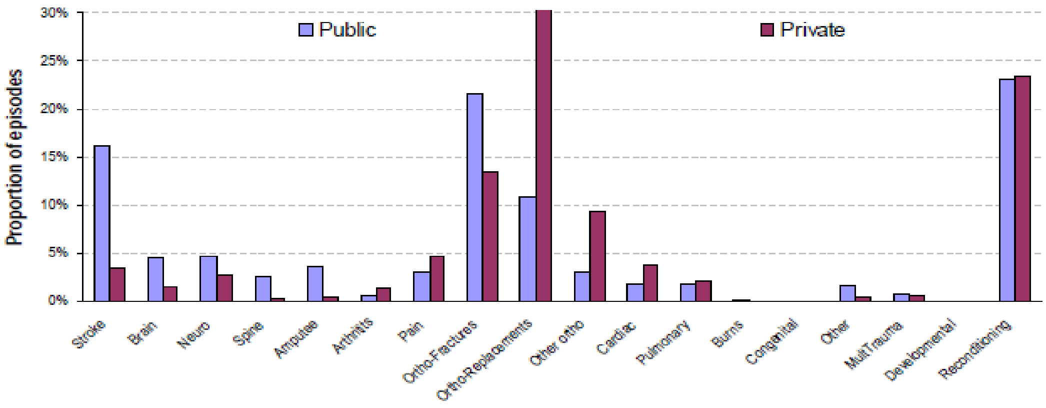
Figure: 1 shows the number of episodes for all impairment groups for 2011. The four main impairment groups were orthopaedic-replacements (19,353), reconditioning (18,319), orthopaedic-fractures (12,930), and stroke (6,438) (AROC, 2012a).

Figure: 1 Number of inpatient rehabilitation episodes by impairment group 2011



There were some differences in impairment group episodes between the private and public rehabilitation sectors. For example, the proportion of stroke episodes was 16% of the total rehabilitation episodes in the public sector compared to 4% in the private sector. Orthopaedic-replacements was greater in the private sector (30%) compared to 11% in the public sector (AROC, 2013a). These differences contribute to overall shorter length of stay reported for the private sector, as joint replacement length of stay is on average less than stroke length of stay - see Figure: 2.

Figure: 2 Proportion of episodes by impairment groups and sector

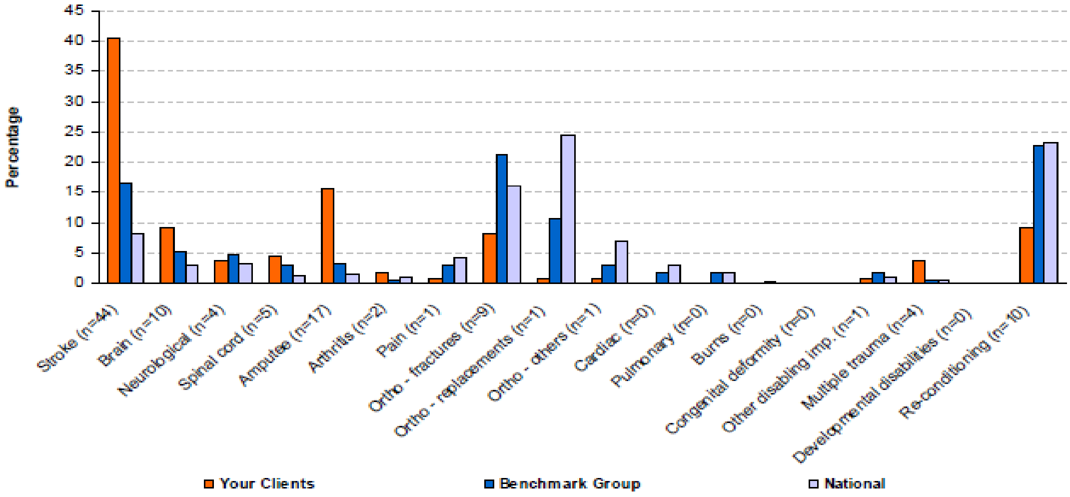


<u>Episodes of rehabilitation care at Royal Darwin Hospital</u>

AROC provide yearly reports to individual rehabilitation member facilities which includes comparison with the national data set and a comparative benchmark facility (AROC, 2012b).

In the AROC report for July 2011 to June 2012, 109 patient episodes were recorded for the 18 bed inpatient rehabilitation unit at Royal Darwin Hospital (RDH). The impairment types included stroke, brain injury, spinal cord, orthopaedic, amputation, reconditioning and others. The three largest impairment groups were stroke (n=44), amputation of limb (n=17) and reconditioning/restorative (n=10), (AROC, 2012b) – see Figure 3.

Figure: 3 AROC Episodes by Impairment Group – for Royal Darwin Hospital (RDH) 2011-2012



There were some notable differences in patterns of rehabilitation episodes by impairment group from the public benchmark group and national dataset as a whole. For example, the proportion of stroke (40%) and amputee (16%) in the RDH rehabilitation service data set were higher than both the benchmark and national percentages (AROC, 2012b).

On average, RDH rehabilitation inpatients were younger; 80% were below 65 years compared with 25% in the benchmark group and 22% for national (AROC, 2012b). These figures reflect the younger population in the Northern Territory (NT) compared with Australia as a whole (ABS, 2010). The burden of chronic disease and lower life expectancy recorded in the Indigenous population in the NT (AIHW, 2012) also contributes, as Indigenous inpatients generally comprised 30% of the rehabilitation inpatients at RDH (Widdall, 2008). Life expectancy statistics summarised in Table 3 show the estimated gap in life expectancy at birth between Indigenous Australians and all Australians is about 11.3 years for males and 10.2 years for females. Life expectancy for the Indigenous population in the NT is the lowest in Australia, being 16.8 years for females and 19.7 for males (AIHW, 2012c).

Table: 3 Indigenous life expectancy at birth based on enhanced death data (2001-2006), for each State, all of Australia and compared with non-Indigenous life expectancy (source: AIHW, 2012c)

	Males	**Females**
New South Wales	69.4	74.7
Victoria	69.2	77.2
Queensland	66.5	72.6
Western Australia	63.4	68.2
South Australia	62.7	68.7
Northern Territory	58.2	66.1
Total Australia -Indigenous	66.6	72.7
Total Australia Non-Indigenous	**77.9**	**82.9**

Inpatient rehabilitation length of stay generally compared with benchmark and national data sets across most impairment groups. However, length of stay differed for amputation of limb (being 49 days) and spinal cord injury (20 days) longer than the benchmark and nationally.

Having provided background and context, the next section discusses literature pertaining to issues that arise with discharge from hospital and for life after rehabilitation.

Issues relating to hospital discharge

The Australian Commission on Safety and Quality in Health Care (ACSQHC) notes "patient discharge from the hospital to the community, is a particularly high risk scenario due to the potential impact of poor discharge processes, poor communication and differences in information quantity and quality" (ACSQHC, 2011, p, 1). As well as identifying hospital to community handover as a high risk scenario, certain patient characteristics or circumstances are also deemed to be high risk. 'High risk' patients are identified as "having specific clinical and social needs which need to be taken into account when planning for the hospitalisation and post discharge phase of care, and who are likely to require care management" (Queensland Health,1998, p. 23). High risk patients identified included those characterised by:

- co-morbidities and complex conditions
- readmissions to hospital
- extended hospital stays
- multiple readmissions over the previous three months
- premature admission to residential care
- failure to recuperate at home
- aged 75 years and over
- the frail aged
- socially isolated patients with no social or family support
- Aboriginal and Torres Strait Islander people 60 years and over (Queensland Health,1998).

The Centre for Allied Health Research (CAHE), (2008) suggests the need to ‘flag’ individuals with high risk characteristics who may prove difficult to discharge safely (p.4). Planning for discharge involves complex and often cyclical processes (CAHE, 2008), and the bed management approach to discharge as an operational matter of service efficiency competes with the values of safety and quality discharge practices intended for achieving fundamental wellbeing of the person. The dissonance between these two approaches can only be exacerbated in situations of increased patient complexity.

In addition, systems issues and constraints external to the hospital setting impact upon the capacity to balance the differing elements to achieve admission and discharge safely. For example, the aging population and increasing numbers of people living with chronic diseases and disability results in increased demands on the acute health sector with a finite number of available hospital beds (AMA, 2013; Harrison et al., 2013; 2003; New & Poulos, 2008). Lack of access to community supported accommodation and insufficient nursing homes beds delays discharge (Health Board Executive, 2003; New & Poulos, 2008).

Distinguishing between issues arising from the bed management approach to discharge and issues relating to person centred quality approach is not straight forward due to the interactional effect between the system elements of discharge. Universally in the literature, discharge from hospital is reported as having a range of challenges. Pressure to control costs by shortening the length of stay, to ensure patient flow, and pressure from patients behind (those waiting in emergency for admission) are factors that can push discharge, often before full resolution of health needs (Bowles, Naylor & Faust, 2002; Proudlove, Gordon & Boaden, 2003).

Patterns of higher separation rates have been found on days when escalation strategies have been implemented in response to overcrowding in emergency departments (New & Poulos, 2008). Significant increases in separations on over-census days were found to be limited to those patients considered long term admissions (over 10 days) discharged from the medical division (New & Poulos, 2008). The impact of extra clinical activities associated with high occupancy, over-census and consequent increased admissions and discharges upon the quality of discharge has not been determined. However, it could be surmised that pressures to discharge early would make difficult an already complex process.

Consequences arising from the bed management approach to discharge are not as clear or as widely documented as problems arising from gaps and deficiencies relating to the elements of the person centred approach to discharge.

Discharge from hospital has been shown to be a high risk process characterised by fragmented, non-standardised, and haphazard care that leads to errors and adverse events (Anthony, Chetty, Kartha, McKenna, DePaoli, & Jack, 2005; Forster, Murff, Peterson, Gandhi & Bates, 2003). Studies in the United States and Canada have shown that following discharge from hospital, 13 - 17% of patients required rehospitalisation and 25% suffered adverse events. Many problems following discharge were due to inadequate follow up and unresolved medical issues at the time of discharge (Forster et al., 2003; Forster, Clark, Menard, Chernish, Dupuis, Chandok, Khan & van Walraven, 2004; Moore, McGinn, & Halm, 2007).

Transition from hospital to the community can be frightening and dangerous for patients (Dury, 2008), and as a complex process it is vulnerable to breakdown (Jewell, 1993). Problems have been identified around communication and continuity of care, failure to adequately assess needs, lack of staff knowledge of resources available and ineffective coordination (Baumbusch et al., 2007; Dury, 2008; Jewell, 1993; Spehar et al., 2005). Gaps have been identified in the provision of education, medications, equipment, information, communication to and with the patient, family and community service providers and a lack of follow up (Anthony et al., 2005; Baumbusch et al., 2007; Spehar et al., 2005).

Strategies implemented to facilitate efficient, timely and quality hospital discharge include; estimating discharge date on admission, early commencement of discharge planning, and the use of discharge planners to coordinate and facilitate discharge from hospital. Although widely used, discharge planning processes have not been demonstrated as to their effectiveness in terms of hospital length of stay and health outcomes in a Cochrane review (Sheperd, Parkes, McClaran & Phillips, 2008). Additionally, the important element of effectiveness of communication in bridging the gap between hospital and home were not reported in any of the trials included in the review (Sheperd et al., 2008). Research of discharge from hospital in Australia has shown that “successful transition from hospital to community is only partially dependent on discharge planning and community service provision. Personality, desire for independence, life experience and the support of carers are critical to the patient’s successful transition from hospital to the community” (CAHE, 2008, p. 3).

Discharge from the Royal Darwin Hospital rehabilitation service

A retrospective audit of discharge from the inpatient rehabilitation ward at RDH was conducted in 2008 as a quality improvement activity. Concerns regarding the quality of discharge outcomes for rehabilitation inpatients, reports of difficulties experienced and complaints made at or after discharge prompted the audit (Widdall, 2008). The audit, commissioned by the co-director of the medical division, conducted by this author, in consultation with a key group of hospital and rehabilitation clinical management/leaders and rehabilitation clinicians used a six stage clinical audit cycle to guide the quality process (ANAES, 2001).

A rehabilitation discharge audit tool was developed, which amalgamated the hospital requirements of the RDH Nursing Standard 2 – Discharge, AROC data set, relevant ACHS Clinical Indicators relating to discharge and best practice principles gained from an extensive literature search and review. (Refer to Appendix A) Nine standards with fifty-five criteria enabled measurement in the form of a criterion-based process audit, confirming rehabilitation discharge processes as complex and cyclical (Widdall, 2008). The rehabilitation standard areas were:

- Standard 1: Discharge planning started with first rehabilitation team in-patient meeting with regular updating and review
- Standard 2: Integrated team process, with a single point of contact for rehabilitation team functioning and person responsible at ward level for coordination of final separation
- Standard 3: Comprehensive assessment of discharge needs
- Standard 4: Ongoing integrated rehabilitation team discharge planning
- Standard 5: Effective communication and information sharing between rehabilitation team and patient, family, community stakeholders
- Standard 6: Ongoing health management plan developed and agreed prior to discharge
- Standard 7: All aspects of the rehabilitation discharge plan are implemented prior to discharge
- Standard 8: Readiness for discharge is assessed and evaluated ensuring safety and quality of discharge
- Standard 9: Continuity of care and follow up arrangements made (Widdall, 2008).

Ten discharges comprising 5 critical cases where an incident report or a complaint was made, and 5 typical cases were selected for audit from the total 48 discharges occurring between the dates of 1/1/08 and 10/8/08.

Results of the audit found a total service quality score of 60% was achieved. This mean score was calculated from the scores for each Standard, which ranged from 37.5% (Standard 5), to the highest 77.5% (Standard 1). Total quality scores for each case ranged from 19% to 97%.

There was only a 9% difference between the total quality score for ‘critical’ cases (56%) and ‘typical’ cases (65%). This unexpected finding was due to operation of similar factors causing deficiencies of discharge in both sub groups. This indicated the potential for hidden deficient factors operating across the total population of 48 discharges in the audit time frame (Widdall, 2008).

When performance against the criteria within the Standards was examined, service strengths and deficiencies were identified. For example, strengths were consultation with the patient, team assessment and regular team review, and use of trial leave to determine readiness for discharge. Deficiencies found included team assessment and discharge planning for short stay patients, inconsistency with documentation of discharge planning, home visits and family meetings, development of health management plan, contact with GP, timely dispatch of discharge letter and communication issues with the case manager. In addition, it was found that a deficiency in one area could result in a critical discharge experience, when overall the quality score in other standards was adequate. Issues with rushing discharge processes just prior to separation, ensuring readiness to discharge and clarification of roles and responsibilities were highlighted (Widdall, 2008).

Information collected on discharge destination for the total number of 48 discharges, found that almost 40 % of inpatients were discharged to areas outside the Darwin region where there were no follow up rehabilitation or therapy services, and limited support for people with disability. This factor was found to further complicate discharge planning and lengthen hospital stay (Widdall, 2008).

The retrospective discharge audit enabled a snapshot of demographic information of the service and service users, and was helpful in identifying a range of activities intended to assist safe and effective discharge. Service review of the results of the audit and of the qualitative information collected was intended to enable service improvement and completion of the quality cycle. Although conducted in response to problems identified with discharge processes, the limitation that outcome information and perspectives on quality of discharge was not gained directly from the patients and families of the audit sample was recognised. Therefore, it was suggested that interviews of patients and their families regarding discharge would provide an additional source of valuable information. As a consequence the current study was conducted.

Life after inpatient rehabilitation

There is a dearth of literature describing experiences of life after discharge from a mixed or general rehabilitation inpatient service. There is, however, studies of experiences for specific diagnostic groups with time frames ranging from within a week to some months or years following discharge. Studies post stroke are most common in the literature and although differing in methodology, common themes relating to psychological and psychosocial concerns occur.

Similar to the documented difficulties with hospital discharge, issues of poor communication and liaison have been identified in quality of discharge following stroke just after discharge and 6 weeks later. Criticisms were made of a narrow focus of rehabilitation, concentrating on the assessment and provision of basic home care and activities of daily living required to obtain discharge, with discharge being seen as an end in itself (Tyson & Turner, 2000). Mixed experiences of discharge following stroke rehabilitation occur when there is variation to support provided, lack of information and differing expectations for continuation of recovery. Clarity of discharge plans is particularly needed at time of discharge, to reduce uncertainty and minimise negative perceptions of discharge experiences (Ellis-Hill, Robison, Wiles, McPherson, Hyndman & Ashburn, 2009).

Life after stroke rehabilitation is affected by multiple factors and the trajectory of functional recovery is not always straight forward. For example, quality of life and functional status measured at time of discharge and then 6 months later showed decline in functioning (Hopman & Verner, 2003). However, in another study 1 month and 6 months post discharge improvements in functioning were linked with self-efficacy. Psychosocial factors, such as self-care self-efficacy, quality of life, and depression, were demonstrated to greatly impact on the recovery process (Robinson-Smith, Johnston, & Allen, 2000).

With further time following stroke, despite being relatively unsupported, by 12 months people were beginning to discover the extent to which they may, or may not, be able to resume valued activities. Resulting in recommendation and recognition for the focus for rehabilitation intervention to identify valued activities and ways the person could be assisted to participate (Robison, Wiles, Ellis-Hill, McPherson, Hyndman & Ashburn, 2009).

Making sense of changes and aligning them with an understanding of change occurring as part of aging and overall effect of other health concerns has been viewed as a biographical flow and biographical construction of the self, rather than stroke being a disruption. These adjustments following stroke were found to occur 1 month, 6 months and 12 months post discharge (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004). The experience of living with stroke viewed as a psychological transition has been described as incorporating five major themes: 1) change, transition and transformation, 2) loss; 3) uncertainty, 4) social isolation, and 5) adaptation and reconciliation (Salter, Hellings, Foley & Teasell, 2008, p. 597). The person had less concrete goals than the health professional; they pertained to personal identity, finding new roles or defining a new sense of normal (Salter et al., 2008).

In Australia, recovery and life after acquired brain injury was found to have distinct transition phases. In the early (1-2) months of coming home when the person first starts to realise the effect of their brain injury and experience unanticipated difficulties, need for support with physical and psychological adjustments after leaving hospital were recommended (Turner et al., 2007). Coping over time with changes due to brain injury required adaptation. Phases of confusion, becoming increasingly aware of limitations, following advice and instructions until being able to alter perceptions of what was helpful were experienced. Adaptive responses culminated in being able to proactively identify own goals and adapting strategies (Shotton, Simpson & Smith, 2007).

Life after and adjustment to spinal cord injury has been described as a lengthy, on-going, dynamic and cyclical process which continues over many years. Initially, basic necessities such as housing, homecare, medications, equipment, transportation, and funding need to be addressed, however often forgotten are needs for counselling and psychological support (Sloan & Wilgosh, 2005). Years after discharge from acute inpatient rehabilitation, perceived information needs were not fully met in areas relating to ageing, research, financial aid, and education for 60 % of a study conducted with community dwelling people with spinal cord injury in the United States (Gontkovsky, Russum & Stokic, 2007).

Following lower limb amputation, peer support, ‘psycho-education’ and information to assist with adjustment and coping were identified as being needed to address unclear expectations. Being vague and uninformed led to uncertainty and passivity, and expectations of a return to normality appeared to be an important part of coping. Exploration of a new normal, both physically and psychosocially, as part of the rehabilitation process was required (Ostler, Ellis-Hill & Donovan-Hall, 2013).

Psychological and psychosocial aspects of life after rehabilitation are evident in the literature across different diagnostic groups, internationally and following brain injury rehabilitation in Australia. However, the focus of inpatient rehabilitation is often on physical recovery, that is, the acquisition of motor skills to improve functional abilities (Rittman, Faircloth, Boylstein, Gubrium, Williams, Van Puymbroeck & Ellis, 2004; Cott et al., 2007; Ellis-Hill et al., 2008). This focus is not congruent with the psychosocial needs being identified post discharge from rehabilitation. There appears to be a dichotomy between the importance of psychosocial transition for the individual and their family, and the extent to which psychosocial transition is acknowledged and incorporated into rehabilitation service provision. Issues relating to relationships, sense of self and views on life and maintaining control, which contribute to a positive transformational outcome, are largely overlooked (Cott et al., 2007; Sloan & Wilgosh, 2005).

Support required with managing rehabilitation as a transition, in the form of preparation for discharge from inpatient rehabilitation services, for continuity while transitioning and following, while engaging in transformation and reorientation is mostly of a psychological nature (Cott, 2004; Ellis-Hill et al., 2008; Kirkevold, 2010; & Turner et al., 2007).

Summary

The literature provides insights into the complex interplay of system elements that operate and influence the quality of discharge from hospital. Compounding factors include the tension between meeting the standards for quality person centred discharge and the organisation, system and service requirements for streamlined access to hospital beds, and for patient flow and throughput. Complexity of patient characteristics being met within the hospital and health system, add to the risk factors and there is a need to attend to the quality aspects of discharge to ensure safety and continuum of care.

These system elements are further compounded by factors external to the hospital system, such as the increasing demand for acute health service access, blockages at exiting hospital with lack of adequate community/disability support services and alternative accommodation options. Achieving a streamlined patient journey, which is underpinned by best practice, is challenging when considering all these competing factors.

The rehabilitation inpatient has specialised needs for rehabilitative care and for discharge. The ‘high risk’ patient characteristics identified, apply to many rehabilitation inpatients and experiencing multiplicity of these characteristics is not uncommon. In view of discharge in general from hospital, being a ‘high risk scenario’ and the compounding effects of ‘high risk’ patient characteristics, it could be deduced that rehabilitation inpatients are more susceptible to difficulties, with greater or more specialised needs when it comes to discharge and discharge planning.

The literature highlights the uncertain trajectory faced after rehabilitation for some diagnostic groups, and that much of the process individuals are engaged in is one of transition and psychosocial/psychological adaptation.

There is a lack of research relevant to transition from a mixed rehabilitation setting, within the Australian context, and in particular while the person is experiencing the transition. Research conducted is limited mainly to stroke, and a qualitative study that did focus on the transition phase for people with acquired brain injury, was conducted retrospectively; requiring memory of experiences occurring 2-53 months beforehand. Most research on the quality of discharge planning reports on perceptions of hospital staff and is focussed on technical and process aspects. There is very little research from the perspective of consumers (CAHE, 2008).

A clinical audit conducted at the study setting, while confirming discharge processes were complex and challenging, was not designed to capture the perspectives of the users of the service. By exploring experiences of the person shortly after leaving hospital, important insights can be gained and assist in refining service delivery, while contributing to the body of knowledge from the person's perspective.

Purpose of the study

The purpose of this study was to find out about the experiences of discharge, transition and life after inpatient rehabilitation shortly after leaving hospital and over the next few months. The researcher was interested in exploring the individuals' experiences and perceptions to better understand needs for preparation for discharge from inpatient rehabilitation and following discharge. The focus of the study was on individuals who had unexpectedly required rehabilitation for non elective physical rehabilitation services (not psychiatric), and not following an acute illness where full recovery was expected.

Research question

The study was guided by the following question:

> What are the experiences of people who have suffered an unexpected and serious health event with impairment to body structure and/or body functioning, requiring rehabilitation in a mixed inpatient rehabilitation service in Australia, when leaving hospital and while adjusting to life in the community?

Study aims

This study aims:

- To explore the lived experiences of discharge and transition from a mixed inpatient rehabilitation to the community in Australia
- To explore experiences and perceptions in 'real time', that is, while individuals are experiencing the phenomena to be studied.

Significance of the study

Exploring the experiences of discharge and transition from inpatient rehabilitation from the perspective of the person allows individuals, carers, and health professionals to gain insight into the issues faced and complexity of needs. Understanding the issues faced and gaining insight into the nature of rehabilitation experiences while preparing for discharge and after leaving hospital of this population, provides opportunity to improve quality of care and relevance of service provision. Using qualitative research to understand the lived experiences will provide rich information and a unique perspective.

Overview of the thesis

This thesis is presented in four chapters. This chapter provided a review of the literature and outlined the purpose and aims of the study. Chapter Two outlines the study methodology and research process. Chapter Three presents the findings of the study, while Chapter Four discusses these findings.

Chapter Two: Methodology

Introduction

In this chapter, the methodology guiding this qualitative study is presented. The research focus explores the lived experiences of people who have suffered an unexpected health event affecting their functioning. Participants with a range of conditions were recently discharged from a mixed inpatient rehabilitation service located in an urban but remote region of northern Australia. The setting, participants and processes used during the study are outlined, including ethical considerations, sampling, recruitment, consent, data collection and analysis. In addition, strategies employed to enhance the rigour of this study are described.

The research focus

The study aimed to explore the lived experiences and perceptions of individuals with impairments to body structure and/or body functioning following discharge and transition from mixed inpatient rehabilitation to the community.

Exploring the experiences and perceptions in 'real time', that is, while individuals were returning to participation in life activities in the community, was of vital interest to the researcher. The time shortly after leaving hospital and for some months after, was the period of interest, with participants providing accounts of their experiences as they occurred over time.

The interactive and interpretative characteristics of qualitative research are influenced by the researcher’s view of the world, which according to Rossman and Rallis (2003) requires awareness and ability to question and explore.

Acknowledgement by the researcher and awareness of the influence of experiences in the clinical setting as a rehabilitation nurse is incorporated in the reflective and reflexive research process adopted, ensuring the study was systematic and rigorous. The researcher sees people humanistically, as functioning beings, capable of thinking, making decisions and motivated by their own sense of what is important. This fits best in a constructivist paradigm, which as explained by Denzin and Lincoln (2003) as having an ontological position where there is an assumption of multiple realities and an epistemology that adopts subjective construction and co-construction of knowledge by human consciousness The researcher's beliefs and values formed from working with people with newly acquired disability occurring as a result of a range of health/events conditions and supports a subjectivist stance where understanding of reality is formed through personal experience, interaction and discussion (Rossman & Rallis, 2003).

The philosophical paradigm and interest of the researcher in understanding the experiences and needs of individuals in the early months after leaving hospital, led to a broad research question being adopted. This allowed for study participants' stories describing their subjective meanings and experiences to shape the conduct of the study.

Research design

A qualitative, descriptive design was used that would enable thematic analysis, as described by Braun and Clarke (2006), of participants' stories and narratives as they were living with and experiencing the phenomena of interest. Persons with a range of conditions were included to provide rich information about their post inpatient rehabilitation experiences, perceptions of their needs and how they responded to leaving hospital and returning to their lives following an unexpected health event.

The study used a descriptive qualitative design. This approach is concerned with "understanding of experiences and behaviour, and the meanings and interpretations that people attach to these" (Holloway, 2008, p 3). Furthermore, the values of person-centeredness and uniqueness of the individual, which is inherent in research that seeks to explore the "insider view" (Holloway, 2008 p 4), embodies the purpose and focus of this study.

Data were collected in a manner that would allow for participants' views and experiences to be expressed with as little direction or influence from the interviewer as possible. Questions were kept to an open ended style encouraging rapport and sharing of information. The interview process is described in more detail later in this chapter.

Transcripts of semi-structured interviews were analysed inductively as this method is useful when there is not former knowledge about the phenomenon to be studied and the data from participants has primacy (Elo & Kyngas, 2008). The six phases of thematic inductive analysis as described by Braun and Clark (2006) were used to guide data analysis and interpretation. Rich and detailed information was gained, and data were coded in an open way without trying to fit into a pre-existing frame of reference. As inductive analysis is data driven (Braun & Clarke, 2006; Elo & Kyngas, 2008) it is a suitable method to understand stories recounted by participants of this study. How Braun and Clark's (2006) six phases of thematic anlaysis were applied during data analysis of this study, is described in the following section.

The research process

The following section outlines how the study was conducted, providing an overview of the setting, ethical considerations and participants. Procedures related to data collection and analyses are also described.

It is noted there is a difference between the study aims described in Chapter One, and the original research design. The original design included family members as well as adult partcipants recently discharged from inpatient rehabilitation. However, data collected from family members has not been analysed or reported in the findings of this study. The decision to limit the thesis report to anlayis of adult particpants only, was due to the amount of data to anlayse which would exceed the requrements for a masters thesis and there were only 3 family members' data. The original design also included the intention to collect and anlayse data from a series of three interviews from partcipants recently discharged from inpatient rehabilitation. Due to a range of factors, some particpants were unavailable for the third interview within the approved research time frame. Two third interviews occurred but this data has not been included in this study.

Setting

This study was conducted in Darwin and nearby areas, in the Northern Territory (NT), Australia. Darwin is a small city located on a strategic naturally occurring deepwater port positioned at the top end of the NT and is geographically Australia's closest port to the South East Asian region. The NT has a small population (approximately 200,000) dispersed over one sixth of the Australian land mass (more than 1.3 million square kilometres). The population of the NT includes a diversity of cultures and languages, (60 nationalities and 70 different ethnic backgrounds) with

Indigenous people comprising approximately 30 per cent of the population in 2011, compared with 3 per cent nationally (Australian Bureau of Statistics, 2013).

The study involved patients recently discharged from the 18 bed mixed inpatient rehabilitation ward at Royal Darwin Hospital (RDH). RDH is the primary acute care facility and specialist referral centre for the NT, providing a wide range of services, it caters for the population of the Darwin region and outlying communities and other centres in the NT and the top of neighbouring states. The "catchment" also extends to include aero medical retrievals from South East Asia.

Clinical presentations can vary widely in inpatient rehabilitation at RDH; including stroke, brain injury, spinal cord injury, orthopaedic, amputation of limb and more unusual topical diseases such as melioidosis. Data from the AROC report in the introductory chapter provides information about the diversity of diagnostic groups. It is not uncommon for younger patients (30-40 years old) to present to the service with stroke and co-morbidities expected in an older population, due to the burden of chronic disease and younger population in the NT. Diversity of patient needs requires flexibility and generalist rehabilitation skills as well as specialty knowledge.

Ethical considerations

Approval for the study was obtained from the Human Research Ethics Committee of NT Department of Health & Families and Menzies School of Health Research (NT & Menzies HREC) and the Flinders University and Southern Adelaide Health Service Social and Behavioural Research Ethics Committee. Additionally, approval was gained from the Larrakia Nation as the traditional owners in the area of the study setting (see Appendix: B). The main ethical issues considered in this study related to confidentiality, recruitment, consent, culture and language, beneficence and separation of the clinician and researcher role.

Participants were assured of confidentiality with no identifying information within the thesis or any other forms of publication. Interviews were recorded and participants given a code. Recordings were transcribed by a professional transcribing service and any identifying information was removed from transcripts. Interviews and one master file with identifying information were kept secure in password protected computer files and hard copies in a secure locked filing cabinet. During the writing of the findings in addition to the above measures, it was decided to not provide information within the written report of diagnoses with participant's assigned number code in the demographic data. As Darwin is a small city with only one public rehabilitation service it was felt necessary to minimise any chance for recognition of participants.

Care was taken in the recruitment and consent procedures to minimise any feeling of pressure and to ensure that potential participants had time to read information sheets and give informed consent. Recruitment and consent was undertaken by someone external to the study, who did not provide direct care to potential participants in the rehabilitation inpatient service. Details regarding recruitment and consent procedures are described later in the chapter. Participants were informed they could change their mind regarding consent and withdraw at any time.

It was determined that potential participants would need sufficient capacity with English to be able to read and understand the information sheet provided and the consent form, and be able to participate in interviews with the principal researcher as interpreter funding was unavailable. Only potential participants who were known to have sufficient capacity with English were invited to participate in the study. This aspect was determined informally by the researcher and person undertaking recruitment. Potential participants for whom English was a second language but had not needed interpreters during their hospitalisation were considered. Plain language was used in the information sheets and were reviewed by the NT & Menzies HREC, to ensure the information provided and design of the project was culturally appropriate. Consideration of and respect for culture, beliefs, individual perceptions and customs was considered during interviewing. Participants were given the opportunity to choose, the time and location for interviews and could invite someone to be with them when interviewed.

The study also considered issues of beneficence as there was a concern that participants could become emotionally distressed during interview. The study design aimed to minimise this risk by ensuring voluntary participation, by providing close monitoring during interviewing and the offer of referral to support services if needed. While some participants did become emotional at times, they did not want to halt the interview. One second interview was ended prematurely when the participant indicated fatigue and pain.

The principal researcher was a clinical nurse employed within the rehabilitation service at RDH. The researcher's usual role in the clinical setting as clinical educator minimised direct contact and provision of daily care to potential participants while they were inpatients and had no clinical relationship with participants after discharge from the inpatient unit. During data collection, care was taken to ensure participants understood the role of the researcher as distinct from the clinical role. At times this was difficult for the researcher but self-awareness and reflection aided in minimising issues. If, during an interview, the researcher became aware that the participant had questions or concerns relating to matters of follow up care or other clinical issues, referral to clinicians in the service was recommended or facilitated. Three participants in the first interview and one participant in the second interview needed guidance about how to seek assistance or facilitation with referral by the researcher.

The decision to not analyse the data collected from participant nine was made after it became apparent there was difficulty with separation of roles and potential for bias. In this circumstance the participant had returned to a trial of work in close proximity to the researcher just prior to when the second interview was due to be conducted. Data from the first interview for participant nine was therefore not analysed and the second interview was not carried out due to concerns of the principal researcher at the time of increased familiarity and support needed by the participant which created these ethical concerns.

Participants

Inclusion criteria required participants to be 18 years or over and recently discharged from the RDH inpatient rehabilitation unit to the Darwin region. Recently discharged meant partcipants were recruited just prior to dishacrge (described in more detail in Recruitment and Consent) and had been out of hospital for a short time frame before participating in the first interview. This time frame varied and is described in Data Collection. Particpants needed to have sufficient understanding of English to read and understand the information sheet, to give informed consent and and to particpate in an interview.

Therefore, excluded from the study were persons who lived on nearby islands or on the mainland more than 100 kms from the Darwin city centre . Also excluded were persons who did not have sufficient English and required interpreter services and persons who were consdered ‘incompetent’ and under legal Guardianship or were awaitng Guardianship due to severe cognitive defictis.

Sampling

A purposive sampling method was used to ensure variation of clinical conditions as this reflected population charactersitics of the general inpatient rehabilitation service. This method of sampling promotes diversity and depth of information obtained so that the aggregate responses reflect the diversity of experiences of the population (Patton, 2002). The size of the sample was pre-determined to allow for some attrition over the course of three interviews and initially aimed for ten adult participants who met the inclusion criteria and their family members.

Recruitment and Consent

The principal researcher identified potential participants from a list of current rehabilitation inpatients in the week prior to their discharge. Identification of potential participants occurred opportunistically requiring a forthcoming discharge date and meeting of inclusion criteria. Other than identification of potential participants, the principal researcher was not involved in recruitment in the study setting prior to discharge.

An independent person not involved in the research project provided written information and explanation about the research project to potential participants and invited them to participate. Potential for compromising the voluntary nature of consent was minimised by not approaching potential participants until a discharge date was confirmed and time given to think about participation. The following day potential participants were met to answer any questions and determine if they were interested in participating in the study; informed consent was sought at this time.

Participants who signed the consent form were asked to provide contact details so the principal researcher could phone them after discharge. The researcher contacted these participants, ensured they understood their role in the study and arranged a convenient place and time for the first interview. Participants consented to three digitally recorded interviews which were expected to take around 45 minutes. A copy of the Information Sheet and Consent form is provided in Appendix: C. Included in the explanation and information given regarding the research project potential participants were informed they could withdraw at any time. This was reinforced verbally when contacted to make a time for first interview and at time of each interview. Participants were informed at time of consent and when arranging interviews, that they could invite a family member or friend if they would feel more comfortable to have someone with them for the interview. Nine particpants and four family member particpants were recruited and two particpants chose to have friend or family with them but were not partcipants to be interviewed. As noted previously the first interview from one partcipant and their family member was not included in the anlaysis and subsequent involvement in the study was suspended for ethical reasons.

Data Collection

Data were collected via semi structured interviews and field notes made after interviews provided further contextual information which was considered during data analysis. Pilot interviews were not carried out; however practice of interview skills did occur with guidance from the principal supervisor.

Due to the detail and amount of total data collected and for purposes of meeting requirements for this thesis, the data analysed and included in this report has been limited to first and second interviews, and excludes data from family participants and participant nine. Data included for analysis and reporting came from fifteen interviews with eight participants, and was collected between the 29/10/2010 and the 15/11/2011.

Demographic data

Demographic information was collected informally during the interview process and information on reason for admission to rehabilitation and approximate length of stay was gained from participants. Of the eight participants, five were male and three female. Ages ranged from 40 years to 81 years and one participant was Indigenous. Participants had a variety of reasons for being rehabilitation inpatients and these health events are broadly categorised as traumatic and non traumatic cerebral neurological conditions, spinal neurological conditions and lower limb amputation to protect confidentiality.

Semi-structured interviews

The original research design planned for face to face interviews conducted by the principal researcher, beginning within one week of discharge. However, due to availability of participants and researcher the schedule was modified. The data from fifteen interviews is included in this report.

The timing of the first and second interviews is set out in Table: 4. Eight first interviews were conducted within four weeks of discharge and seven second interviews 10 - 29 weeks from time of discharge. One participant was unavailable for second interview due to personal requirements to be interstate. The wide time frame for second interviews was partially due to availability of participants and researcher.

Table: 4 Timing of Interviews following discharge(D/C)

Participant number	**First Interview** (days/weeks from D/C) ***Range 4 days – 4 weeks***	**Second Interview** (weeks from D/C) ***Range 10 weeks -29 weeks***
1	4 days	10 weeks
2	3 weeks	12 weeks
3	3 weeks	16 weeks
4	2 weeks	13 weeks
5	4 weeks	29 weeks
6	2 weeks	Unable to interview
7	6 days	23 weeks
8	1 week	24 weeks

Questions during the semi-structured interviews were open ended and general to allow participants to communicate their experiences and perceptions freely. Prior to interviews a guide was developed (refer to Appendix: D) to enable consistency of a few key topics relevant to the focus of the study. However, the researcher used general wording and did not read from the guide, ensuring that similar main questions were asked. This allowed for exploration of participants' experiences without using fixed wording or order of questioning. Key questions gained information from participants on why they were in rehabilitation, any preparation for leaving hospital (first interview) and experiences since leaving hospital. During the second interview, participants were asked general questions about experiences since the first interview. Other questions related to individual participants stories, to indicate interest, establish rapport and for purposes of clarification and probing where necessary.

During first interviews, initial questions about the reason for being in rehabilitation resulted in participants providing detailed information about their hospital experiences, significant events and perceptions regarding what had happened to them. Other questions about experiences since leaving hospital were interspersed where appropriate. During second interviews, some participants repeated memories of hospital experiences seemingly concerned with significant events that were still fresh in their memory. However, open and general questions about experiences since the first interview provided detailed information of experiences living with changes over time. The researcher established rapport through listening and often topics were discussed that did not directly relate to the focus of the study; this added to the length of interviews, but enabled participants to feel comfortable sharing their stories, and added to the richness of data collected. Some participants became emotional at times when recounting experiences but did not want to stop the interview process.

Participants chose the date time and location for all interviews. The intent was for the participant to feel as comfortable as possible and to not be inconvenienced. All participants chose to be interviewed at their home at a time they determined. Interview length of time ranged from 35 minutes to 80 minutes and was largely determined by participants who spoke descriptively and in detail of their experiences and perspectives.

Field notes

Field notes were kept in a reflective journal and enabled recording of contextual information, perspectives and experiences of the interview process and reflections during data collection. Sometimes these reflections of experiences influenced the research process. For example, the researcher had not expected the amount of information provided by participants about hospital experiences and was surprised and initially overwhelmed with the amount of data to analyse. Encouraging participants to talk and making them feel comfortable by talking about interests in common or topics unrelated to the research focus lengthened interviews. One interesting and initially unexpected finding was when winding down the interview after turning off the recorder; participants started talking again about significant experiences. After this happened twice, the recorder was left on during closing statements to capture this additional data.

Writing down situations as a reflective field note enabled consideration of issues that arose and a better understanding of the potential realities of qualitative interviewing, was obtained. For example, as a novice researcher tension between clinician and researcher roles was experienced early in data collection, when a situation presented by the participant during the first interview, created an ethical and professional dilemma. This situation which is described in the Field journal notes in Appendix: E brought the two roles of researcher and clinician into direct conflict. A clinician response was required to meet the expectations of the professional practice and ethical responsibilities of a registered nurse as set out by the Nursing and Midwifery Board, (2010), and for the safety and healthy wellbeing of the participant. The occurrence right at the beginning of the very first interview was unexpected and confronting to the researcher as the significance of potential difficulty for the participant if by chance the researcher had not been there was realised.

This experience and reflection through use of field notes prepared the researcher for subsequent occurrences when participants had questions or issues relating to instrumental issues following discharge. The researcher was able to employ strategies to enable questions and issues to be resolved through referral to others in a way that minimised conflict with the researcher role.

Data analysis

Interview transcripts were analysed using the six phase guide for thematic analysis as described by Braun and Clark (2006). In this method, patterns or themes are identified and then analysed, reviewed, defined and reported (Braun & Clarke, 2006). While these guidelines are described as linear, they can be applied flexibly, allowing for movement back and forward as needed between the phases (Braun & Clark, 2006). This dynamic aspect of recursive movement between the phases was evident during analysis and interpretation of data which had commenced with first interviews, and was modified and influenced by later analysis of Second Interview transcripts.

Data driven inductive analysis is integral to thematic analysis (Braun & Clarke, 2006; Elo & Kyngas, 2008) and especially relevant for the focus of this study where experiences of participants were unknown by the researcher. The hierarchical nature of inductive analysis means there is a bottom up approach to organising, categorising and giving meaning. Words and phrases in the transcripts are coded and given labels. These initial labels are then sorted and grouped into categories where similar meanings or related meanings can be put together and named to classify and describe the data content. These categories are then organised into broader categories of sub-themes and themes. The corresponding reporting of descriptions and interpretations of the data while derived from the words of the participants becomes more abstract when moving from coding and labelling up the hierarchy to the level of the themes (Elo & Kyngas, 2008). Diagram 1 depicts the hierarchical nature of Braun and Clark (2006) 6 phases of the inductive analysis process.

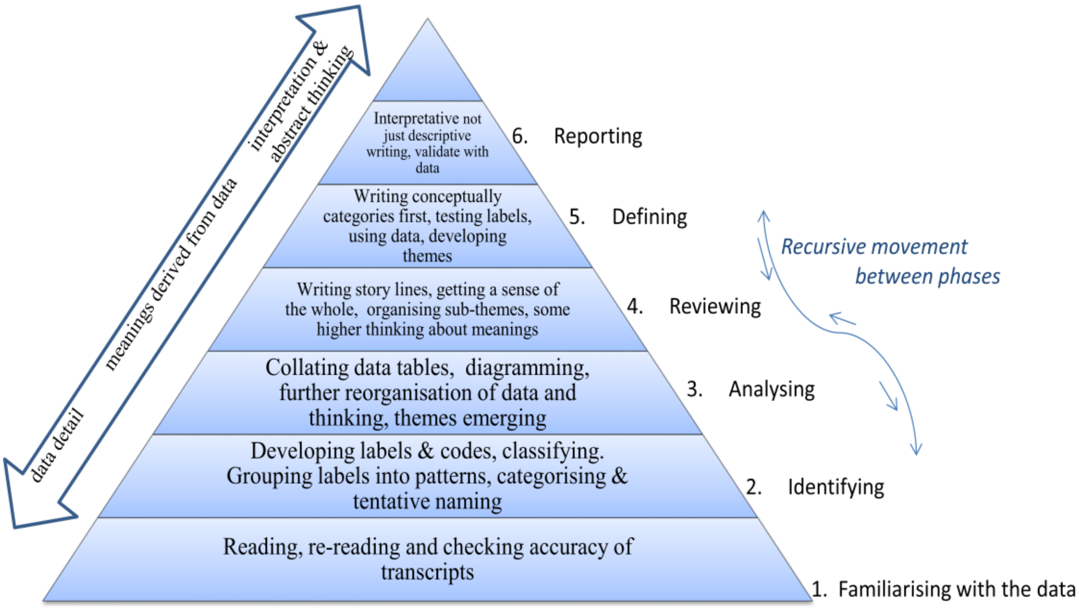


Diagram: 1 Depicting Hierarchy of Inductive Analysis Process - Braun & Clarke (2006) 6 Phases Thematic Analysis

Using Braun and Clarke (2006) phases as a guide, the inductive data analysis process and resultant findings in this study are summarised. The first phase of familiarising with the data involved reading of transcripts, checking accuracy by listening to recordings and ensuring identifying information had been removed. Transcripts were then read and re-read by the researcher to familiarise further with the data. Analysis of the First Interview transcripts were commenced before analysis of the Second Interview transcripts.

In phase two, approximately 68 initial labels were produced from the First Interview Transcripts and approximately 60 initial labels from Second Interviews. To aid in organising, they were put into hard copy format on pieces of paper and spread on a large table, so individual labels could be visualised separately and together. This tactic enabled ‘hands on’ manipulation to check for doubling up of similar coding and for early grouping into patterns. Early impressions of the data set were put onto a white board, enabling checking and testing of data coding and tentative grouping of labels into patterns by the researcher and supervisor. Photos of these data analysis activities are included in Appendix E.

Developing lists of the labels and organising into coding tables under tentative headings for groupings began the third phase of searching for themes with categorisation into electronic format. Use of a data table enabled data extracts to be inserted under labels and categories, which aided verification and assisted during writing up the findings of the study. Notably this process of organising, refined and reduced number of labels and categories and also resulted in checking and confirming criteria for categorisation. For example, 68 initial labels reduced to 20 from First Interview transcripts and 60 to 26 Second Interview transcripts when first organised into the coding tables. This refining process continued through the following phases of the inductive data analysis and data findings were finally reduced to 14 data labels, under 6 categories, 3 sub-themes and 1 overall theme. An interesting finding while analysing the second Interview transcripts were the significant differences in data and consequent new labels and patterns emerging.

Use of the white board and diagramming emerging patterns into themes electronically helped with critical thinking and gaining a picture or understanding of the subject matter within the story of the data. Strong elements were evident in analysis of First Interview data relating to participants coming to a new understanding of changes to their functioning and action related elements seemingly in response to this understanding. Although the naming of categories and sub-themes were modified after further review in later phases, the essential meanings stayed strong. During this early analysis, a group of data was collated under a heading relating to discharge from hospital, further examination and consideration changed the researcher's perspective on the place and importance of this data. While descriptive of the instrumental aspects of leaving hospital the researcher came to realise the stronger and more meaningful experiences of participants coming to terms with unexpected change to their functioning were the key aspects to analyse and report. This response to the emphasis of participant's experiences exemplifies how the inductive analysis process is data driven.

During analysis of First Interview transcripts two particular aspects of the data set were also speaking strongly to the researcher but did not quite fit under the pattern of categories determined. Record of these data labels were kept and later when analysing Second interview transcripts their place and importance became apparent and were identified as contextual elements which were essential in enabling the experiences participants were describing. Other labels relating to personality traits, self concept, emotional and psychological reactions and drive for independence were found to run across all sub-themes and significance was not yet fully understood in these early phases of analysis.

Specific strategies aided clarification and refinement of categories and sub-themes such as, collating data into tables under headings, diagramming and writing description of the data in the form of story lines. Further testing of labels and thinking resulted from using these strategies and through interactive discussion with an experienced researcher. As ideas came to the researcher when engaging in these strategies they were noted in the reflective journal. Later some of these earlier inspirations or ideas became significant. Coding and searching for themes in Second Interviews data revealed new categories and themes that were quite different to the previous analysis of First Interviews data. The dynamic aspects of going back and forwards between data from two sets of transcripts resulted in further thinking about the data components and the data set as a whole. At this time significance of previously unallocated elements began to become clear and there was indication of an over arching story or theme and groupings of labels and categories identified from both interviews fitted underneath becoming sub-themes. An example of an element which became more significant during this phase was explored and labelled ‘re-awakening of the usual self’. When trying to understand what was happening in the data coded as self–concept and drive for independence these concepts became linked in the researchers’ thinking to participants beginning to take action.

Phase four of thematic analysis involved two levels of refining and reviewing themes according to Braun and Clarke (2006), reviewing coded data extracts and checking for a coherent pattern and reviewing the entire data set at the level of the themes. In this study, judging whether data within categories and themes cohered meaningfully and there were clear distinctions between categories and themes came with beginning to write descriptive accounts of each category and theme, using words of the participants (data excerpts) to validate descriptions. During this process the researcher refined and defined what had been 4 sub-themes to 3 and categories underneath reduced from 8 to 6. Forming a sense of the complex nature of the data and rich detailed information resulted in realising that some aspects of the data could not be included for more detailed analysis in reporting this study. At this time it was possible to put together a draft total diagram that included the over arching theme, sub-themes, categories and depicted contextual aspects and other influential elements. Braun and Clarke (2006) call this a thematic map and by the end of this phase the researcher should have an idea of what different themes are, how they fit together and the overall story they tell about the data. Refer to Appendix: G for examples of the theme development.

Reaching this point was an exciting breakthrough moment when a picture conceptualising the whole formed in the researcher's mind, and the imperative became to try and put it all together in a more sophisticated diagrammatic representation. The non linear characteristics of thematic analysis were exemplified with the researcher concurrently working on reviewing themes and phase five of defining and naming themes. Testing and checking for coherence and defining categories and themes occurred together. Renaming when writing and diagramming were natural consequences as the researcher attempted to make findings distinct and descriptive. The other experienced researchers of the study were involved to review the emerging conceptualisation of findings and to confirm definitions and descriptions were distinct and data from transcripts validated interpretations and conclusions.

The final phase of producing the report continued the analysis process as the 'essence' and relationship of themes were confirmed in a story which aimed to be concise, coherent, logical and interesting, with sufficient evidence of themes within the data (Braun and Clark, 2006). Description of data becomes interpretative and inductive as ideas become more conceptual while moving away from the data detail up to meanings in themes, but is derived from the data. Braun and Clark (2006) described this as making a compelling argument which is embedded within the analytical narrative.

Enhancing rigour in this study

Braun and Clark (2006) provide a 15 point checklist which can be used to evaluate the quality or rigour in qualitative research. The way in which the thematic analysis has been performed must be clearly and explicitly described and the 15 point checklist includes: 1) the process of transcription; 2) issues of coding of data; 3) importance of ensuring that analysis and data match and that analytical claims are supported by data excerpts; 4) the overall process of analysis, considering whether all phases have been conducted adequately; and 5) ensuring the underlying theoretical assumptions of a constructivist paradigm and the inductive analysis process are visible during report writing. The details provided in Data Analysis described how the researcher used the six phase guide provided by Braun and Clark (2006) refer to Appendix: H for a summary of the 15 points.

Rigour of a qualitative study is also established when there is evidence of credibility, transferability and dependability (Koch, 2006). This can be achieved by clear and recognisable descriptions of themes emerging and interpretation of the researcher and where awareness and experience of the researcher is described (reflexivity) (Koch, 2006). During the data analysis process, credibility was enhanced by retuning frequently to the transcripts and collated data tables to check meanings ascribed were representative and grounded in the data. Including excerpts of data, provided examples of participants words which demonstrated ideas, concepts and meanings matched the words chosen to name labels, categories, and sub-themes. Discussion and critical review of ideas and patterns developing during data analysis with experienced researchers further enhanced credibility as more than one point of view contributed to the inductive analysis process. Meeting with the experienced researcher enabled face to face interactions and guidance during critical stages, sharing of evolving diagramming and writing descriptions of the findings were essential aspects of the critical review process. Obtaining the views of other experienced researchers not so intimately involved in the data analysis process, provided another objective consideration of the interpretation of the data.

Transferability of findings can be judged with descriptions of context and whether outcomes can be applied to similar circumstances (Koch, 2006). In this study the researcher provided an understanding of a journey of learning experienced over time by participants with a range of conditions which had required inpatient rehabilitation. Description was provided of the experience of limitations in functioning following leaving hospital and re-establishing life activities, the setting in which the study had taken place and demographic information provided by participants was included. Consideration of this information allows determination of whether there is transferability to other similar populations.

Dependability of the process can be audited by following a “decision trail” whereby decisions taken about theoretical methodological and analytical choices are explicit (Koch, 2006). Specific tactics suggested by McBrien (2008) to enhance rigour by; keeping of a field journal, enlisting assistance of 'experts' to review patterns being generated and 'peer debriefing' to assess persuasiveness, coherence and robustness of emerging themes were undertaken. The research process in this study included memos in a reflective journal, each stage of phases in coding and diagramming of category and theme development have been kept and dated providing evidence of thinking and understanding of the data as it occurred.

Chapter summary

This chapter identified the research focus of exploring the lived experiences of individuals with impairments to body structure and/or body functioning as they re-established usual life activities following inpatient rehabilitation. The theoretical perspective underpinning the research has been described as well as the qualitative and thematic research process followed. Qualitative inquiry strategies have been detailed and strategies incorporated to enhance rigour described. The following chapter will present findings of this process.

Chapter Three: Findings

Introduction

This chapter presents the findings of this study. It starts by describing the participants and then presents an overarching theme of *learning to live with the altered functional self*. Three sub-themes: *realising my functional self has changed, taking charge to restore my functional self* and *taking charge of my changed situation* are also described.

The participants

This study reports the findings from eight participants, who had recently been discharged from a mixed inpatient rehabilitation service. All participants experienced changes to their body structures or functioning as a result of an unexpected health event. For six participants the health events were neurological in origin; due to stroke, infection or trauma. The two other participants had lower limb amputation (see Table: 5). These types of health events were the most common reasons for requiring rehabilitation in the rehabilitation service, and from this perspective the eight participants is considered a representative sample of the mixed rehabilitation service.

Table: 5 Summary of participants' condition category

Condition category	Number of participants
Non traumatic cerebral neurological condition	2
Traumatic cerebral neurological condition	2
Combination traumatic and non traumatic cerebral condition	1
Lower limb amputation	2
Neurological spinal condition	1

Participant's level of functioning and independence varied. Functional Independence Measure (FIM) scores were not able to be accessed for this study, therefore only a general functional description observed by the researcher or reported by the participant at first interview is noted for contextual purposes, (see Table: 6).

Table: 6 Participants' observed or reported function at first interview

	Functional status observed/reported incidentally at first interview
Participant 1	Limited mobility, wheeled walker short distances, poor balance, vertigo, reported falls
Participant 2	Slower mobility, wheeled walker for longer distances, some hand function issues
Participant 3	Very limited, wheelchair, transfer with assistance, walking a few steps with support, hemiplegia
Participant 4	Walking, pain on distance,
Participant 5	Nil issues with mobility, restricted from driving, fatigues easily, mild memory issues
Participant 6	Minor mobility limitations, fatigue, moderate memory issues, reading and writing self-described at level of 10 yr old
Participant 7	Wheelchair, transferring, standing, walking a few steps
Participant 8	Able to walk short distances with prosthesis, using crutches

Due to recruitment requirements to live within the Darwin region and to have sufficient comfort with being interviewed in English and for consent purposes, only one participant was Indigenous. Generally, approximately 30% of inpatients of the rehabilitation service were Indigenous, however only a very small number lived in the Darwin region, as most came from remote and distant locations in the NT Territory. Three participants were female and five male, and their ages ranged from 40 years to 81 years. Length of stay in the rehabilitation unit ranged from approximately two weeks to 5 months. Two participants had two rehabilitation inpatient episodes due to complications. One of which had a long complicated stay being in rehabilitation for over a year in total.

Darwin is a small city and the largest urban centre in the Northern Territory, comprising inner city and suburban areas. The Darwin region includes the city and suburbs and semi rural areas up to approx 50 km from the city centre. Four participants lived in the suburban areas and three lived on five acre blocks in the semi rural outer areas of the Darwin region. One participant had accommodation in both localities - see Table: 7.

Table: 7 Study participants, sex, age, and home location

Participant code	M/F	Age	Location of home
P1	M	81	Semi-rural, outer Darwin region
P2	F	77	Semi-rural, outer Darwin region
P3	M	71	Suburb, inner Darwin region
P4	F	52	Semi-rural, outer & Suburb, inner Darwin region
P5	M	40	Suburb, inner Darwin region
P6	M	45	Semi-rural, outer Darwin region
P7	F	58	Suburb, inner Darwin region
P8	M	51	Suburb, inner Darwin region

Key findings

One overarching theme and three sub-themes were identified in this study. The overarching theme, *learning to live with an altered functional self,* describes a journey of learning through experience and adaptive responses to unexpected changes to body structures and limitations in functioning. Processes of realising changes to functioning, taking action and being in charge of a new and changed situation enabled continued participation in valued life activities. The study also found the essential influence of context, through performance of everyday activities in home and community environments, was required for experiential learning throughout the journey. The journey of *learning to live with and altered functional self* began while in hospital and was continuing. See Diagram 2

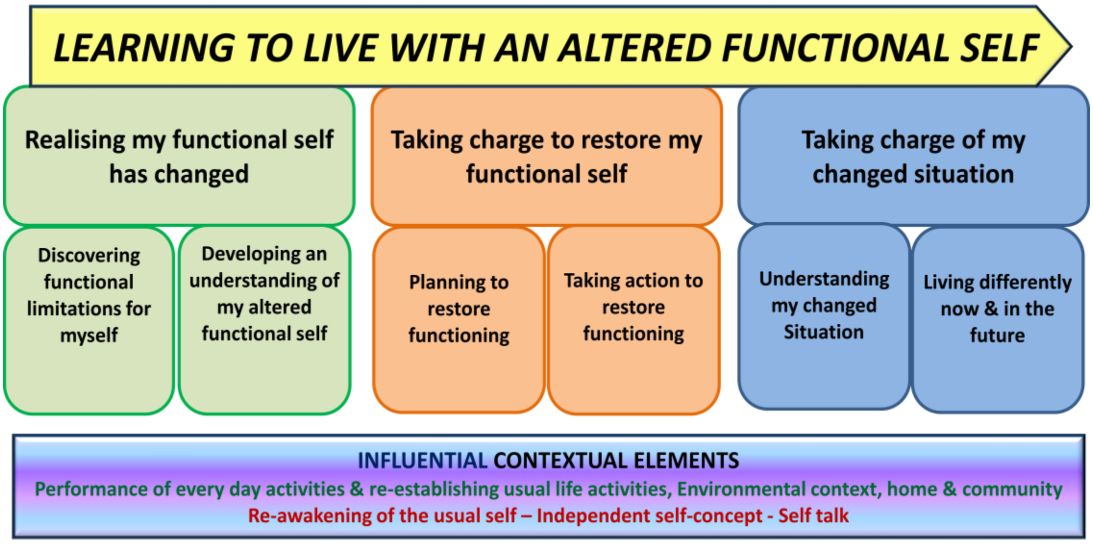


Diagram: 2 Overarching theme: sub-themes, sub-categories, influential contextual elements

Overarching theme: Learning to live with an altered functional self

Learning to live with an altered functional self is the overarching theme found in this study. It refers to a journey of learning through experience and adaptation, following a significant and unexpected health event, where participants came to understand how to live with an altered functional self and continue participating in valued life activities. Changes to body structures and functioning were perceived and experienced as functional limitations. The experiencing of functional limitations while performing everyday activities and while re-establishing usual life activities provided a performance context within which participants came to understand these limitations. These contexts provide motivation and possibilities for actions to restore functioning. Over time, the efforts of participants in using adaptive and productive strategies in interaction with the environmental contexts brought about new understandings of an altered functional self and changed personal situation.

The differing learning components and the experience of changed functional capacity as lived by participants are described in the three sub-themes. While conveyed as a progression, learning did not necessarily occur in a linear or straight forward manner. Some components overlapped, occurring concurrently, others required the element of time for knowledge to be informed by multiple experiences of alteration to functioning.

In the first sub-theme, *realising my functional self has changed,* learning began through discovery of limitations and became known by participants through doing. Participants gained a deeper understanding of the changes to their functioning and effect upon their independence. They came to understand and realise that individual limitations in functioning combined to form an altered functional self.

The functional self was distinct from the whole person 'self' as other aspects of personhood such as personality traits, cultural beliefs and self-concept of independence and individuality were largely unchanged by the functional limitations experienced. The meaning of functioning in the context of this study refers to human functions of body and mind, incorporating the physical, cognitive and behaviour dimensions needed to complete an activity or participate in life roles. The functional self as an aspect of the whole person 'self' fulfils choices for action, incorporates innate assumptions of usual functional performance and includes perceptions of future capacity.

In the second sub-theme, *taking charge to restore my functional self*, participants' focus and actions were directed towards regaining their previous functional capability. Learning by comparing and finding deficits or dysfunction motivated planning and actions taken. This motivation was also derived from participants' view of themselves as independent beings. Hence, learning became purposeful, goal directed, self-initiated, and informed decisions where participants were in control. At some point there seemed to be a re-awakening of the usual capacity for self determination, which had been in abeyance while participants were unwell as their health situation was serious and life threatening. Almost all participants described their initial health event experience in terms of near death and considered themselves lucky to be alive.

Learning in the third sub-theme, *taking charge of my changed situation*, was characterised by the influence of the passage of time and experiencing complex and partial recovery of the functional self, while resuming usual everyday and life activities. Experiencing functional capacity, as the amalgamation of both limitation and capability, over time led to an accumulated knowledge and to understanding of a changed situation. Determining adaptive learning strategies that enabled continued participation in life roles and activities, exemplified being in charge and of living with the altered functional self.

Learning to live with an altered functional self was also characterised by influential contextual elements. These included: the environment, and performance of everyday or life activities, the independent self, and the occurrence of 'self-talk'. Evident within individual experiences were the effect of psychological, emotional responses, and personality traits. However it was the contextual elements which appeared significant throughout the data. The essential influence of context, through performance of everyday activities in home and community environments, was required for experiential learning. The environmental capacity to support and challenge performance and functioning were evident throughout the learning journey, and home and community was essential for learning and adapting, and for the wellbeing of the person.

The sense of an independent self concept was retained despite adversity or the experience of functional limitations, and was expressed repeatedly in participants' stories. Wanting to be independent influenced responses to the experience of the altered functional self, provided motivation and was integral to the locus of control being with participants.

> *Doing what I want to do, when I want to do it and how I want to do it. I'm not being told* (P2.2, 236).

> *The motivation is to walk because I know it will allow me to do a whole host of other things; like that would give me greater independence, it would allow me to get to different places, to appreciate a museum, to go inside. You can go in but it's just nice to walk around. It's nice to walk into a restaurant rather than go into it in a wheelchair. So yeah there are little things like that. But I won't give up. I'll work for as long as I can and as hard as I can do just to see what I can resurrect out of this problem, but only time will tell* (P3.2, 428).

Almost all participants except for one displayed a strong determination to overcome adversity, which seemed to be linked to challenges to living in the Northern Territory they had experienced previously. One participant seemed more accepting and fatalistic about their situation due possibly to a cultural belief. However, they still engaged in problem solving and experiential learning, on a day to day basis. One participant was so determined to walk again that for some time this appeared to be the sole motivator and excessive energy and additional physiotherapy being arranged. Getting stuck resulted in expressions of depression and having to talk himself into a more positive frame of mind when realisations of the unlikelihood of reaching these goals became apparent.

The occurrence of the use of ‘self-talk’ was noted during interviews, where some participants’ included the text of conversations they had with themselves while performing activities. Although the use of ‘self-talk’ was not studied in detail as the occurrence was coincidental, it resonated and added a richness and insight into the inner workings of the individual. The words used seemed to be related to participants thinking about and trying to make sense of what had happened to them. ‘Self-talk’ also occurred when participants were encountering difficulties and appeared to be spurring themselves on. ‘Self-talk’ expressed during interviews seemed to be the verbal manifestation of an internal dialogue and thinking, which occurred during progression of learning through experience.

Participants experienced and described a range of psychological and emotional responses and along with individual personality traits influenced individual experiences. It appeared that physical and emotional pain was experienced and tolerated, and it was apparent that the work of recovery and effort required for learning through experience was intertwined with psychological and emotional work and consequences. The psychological and emotional experiences and feelings communicated represented the human dimension of discomfort as well as the depth of capacity for maintaining hope and determination.

> *Tolerance. I know it’s going to happen, I know it’s inevitable so you resign yourself to it. So they think you’re tough but all you’ve done is resigned yourself to the fact that this has got to happen so let it happen and just grin and bear it. I’m not tough because I feel the pain and I feel shithouse so I’m not tough but I don’t scream out, I don’t yell out, I never ever. I don’t let on at all that it’s hurting* (P1.2, 840). ..... *I’ll come good. I’ve got the attitude to make it come good. I’m not giving in, no way. There’s too much to do to give in, too much to look forward to* (P1.2, 777).

In *learning to live with an altered functional self*, each participant’s learning was unique. However, revealed were consistent features of thinking and internalised processing, which appeared to be occurring throughout hospitalisation and after discharge. The work of recovery through thinking and doing was situated in the context of real life experiences and situations.

In the following sections, the three sub-themes of *realising my functional self has changed, taking charge to restore my functional self* and *taking charge of my changed situation* are described to enable a richer understanding of the lived experiences and perceptions of participants. It is apparent the journey of learning through experience was captured for a period of time and there is a continuing story.

It is important to acknowledge that participants were not alone on this journey, as friends and family provided support and travelled with them, however their perceptions and experiences are not included in the report of this study.

Sub-theme 1: Realising my functional self has changed

Realising my functional self has changed is the first of three sub-themes in *learning to live with an altered functional self,* and refers to the beginning of a learning process where participants came to understand change had occurred to their functional self and the nature of these changes. The learning process commenced in hospital and continued after leaving hospital and was facilitated through experiencing the altered functional self within the context of performing everyday and life activities in home and community environments. Diagram 3 depicts sub categories and components of *realising my functional self has changed.*

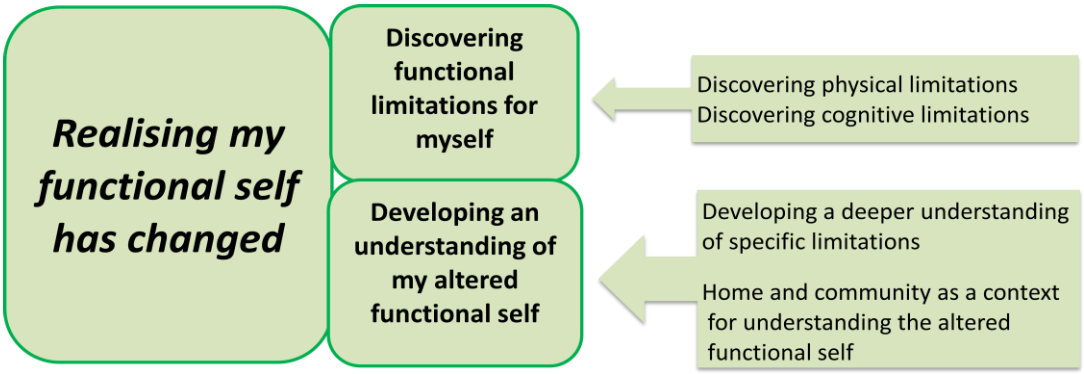


Diagram: 3 Sub-theme 1: Realising my functional self has changed, sub-categories and components

Activation of a longer and complex journey of learning began with participants discovering for themselves physical and cognitive limitations in function and coming to an understanding of their altered functional self. Other aspects of this journey of learning are described in the following two sub-themes.

Learning through experience grew to a process of realisation, with participants coming to an understanding of the effect of limitations of functioning upon the functional self. This process transcended time, incorporating the past, present and their anticipated future perceptions and experiences of functioning. Realising unexpected changes affecting capacity of the functional self became serious for participants when the altered functional self was perceived and experienced as more dependent and the concept of the independent self were challenged.

Learning experiences differed between participants according to their individual circumstances however; learning through experience, ‘knowing through doing’ and intentional learning ‘thinking while doing’ and ‘thinking about experience of doing’ were common features of the nature of learning experientially. Realising that their functional self has changed involved a comparison of the new altered functional self with the previous capable functional self. Coming to realise this change in the functional self is exemplified with realisation that thinking about the functional self has to change:

> *I'm thinking like an able-bodied person and I'm not* (P8.1, 460).

In addition, realising included the future perspective of anticipating doing with the altered functional self giving direction to participants for action.

Two sub-categories are described that comprise the experience of realising change to the functional self and these are; *discovering functional limitations for myself* and *developing an understanding of my altered functional self*.

Discovering functional limitations for myself

Discovering functional limitations for myself refers to the discovery of limitations that became apparent when experiencing bodily impairments within the context of doing everyday activities. While the type of activities undertaken and specific limitations that were discovered varied between individuals, the nature of discovering was similar for all, as participants did not expect the degree of difficulty they encountered.

The discovery of limitations came through doing, that is, participants needed to experience their impaired bodies while performing everyday activities to discover their functional limitations. While participants seemed to possess some knowledge of their bodily impairments, performance provided the experiential context for discovery. There seemed to be a clear difference between ‘knowing about something’ and ‘knowing through doing’, with the latter experienced in the physical sense.

Participants were discovering limitations during activities, the performance of which they had previously taken for granted. Participants were discovering for themselves they had limitations and that activities performed automatically previously were now difficult, different and required effort and thought. Sometimes, participants were discovering that some activities were now no longer possible.

While functional limitations were discovered before discharge from hospital, the discovery process continued after discharge. The home environment enabled the discovery process by providing opportunities for a wider range of activities than the rehabilitation ward. Two types of functional limitations were discovered, namely, physical and cognitive. Collectively participants reported discovery of physical limitations to a lesser extent than cognitive limitations.

Discovering physical limitations

Participants reported discovering three main types of physical limitations. These related to strength, endurance and balance. These physical limitations were not discovered in isolation of each other; they were commonly discovered together because activities undertaken often required a combination of these bodily functions.

For example, during the first interview P4 recalled experiencing difficulty going up stairs when on home leave from the inpatient rehabilitation unit. Climbing stairs required lower limb strength and a certain degree of endurance to get up the full set of stairs. P4 had to force herself to climb the stairs dragging her affected leg behind her. She said, “I never thought about not being able to do it” (P4.1, 554).

When balance was also affected, the discovery of physical limitations was sometimes within the context of a fall. Falls were reported during transfers. For example, when getting out of bed on his own, P1 recalled thinking “I can do it, I feel good” (P1.1, 522). However, he was yet to discover that getting out of bed on his own was no longer safe:

> *I put my leg over the side of the bed and grab my walker and just keep going. Boom, crash, bang, what’s that?* (P1.1, 511).

P7 also had a fall and described it as follows:

> *The other night - no I think I was in my sleep and I got in the chair myself and I got to the bathroom and I held those two irons* [grab rails].....*and I don’t know how the bloody hell I fell down. I had the brakes on and I just fell and hit the back of my head* (P7.1, 169).

P7 discovered that she no longer had consistent strength and balance to execute a safe transfer between wheelchair and toilet.

Sometimes changes to physical endurance were not discovered immediately, but later. In the case of P1, he felt capable while exercising in the pool, but the next day he discovered limitations. On getting out bed the next morning, he found himself to be “stiff as a board” (P1.1, 902).

Discovering cognitive limitations

Participants reported discovering a variety of limitations in cognitive functioning. These related to mathematical calculations, perception and memory. Like the discovery of physical limitations, the discovery of cognitive limitations was enabled by the context of performing everyday activities.

P1 described how he was forced to use his fingers to try and calculate what had previously been simple multiplication and addition during assessment of his mathematical skills. He discovered that he had an “IQ of about grade 4” (P1.1, 229), which meant he was not able to run his business with confidence and without thinking as he had in the past:

> *I thought, oh come on. I said, this is bloody ridiculous. This is what I used to be able to do. Working out - when I get my invoices working out the cost and the percentage and your profit margin and all that sort of thing. It was an everyday occurrence. I just sat back and I just said, this is no good Maggie* [Australian colloquialism] (P1.1, 241).

Discovery of limitations in visuospatial functions and cognitive processing of visual information happened during performance of activities that depended on these functions. For example, P1 felt he could return to driving. While out in a vehicle as a passenger he was asked to look quickly from left to right at an intersection. The experience of dizziness and disorientation led to him discovering for himself that he could no longer drive safely:

> *I'm sitting in the passenger seat. She said just slowly look past me over there. So I just slowly looked past her over there. She said, now there's something coming. There's something coming on your left and beeped the horn. Look, quick. You might hit it. I looked over quick, woo. I grabbed hold of the front dashboard of the Toyota. She said, how are you feeling? I said, I don't even know where I am for a second. She said, and you're going to drive are you? I said, no* (P1.1, 604).

Sometimes discovering perceptual limitations occurred in stages. P5 described how he couldn't understand why he was frequently asked questions about double vision when he was in hospital, until he got up to have a shave, and looked in the mirror. However it wasn't until later when at home that he discovered the implications of this impairment when performing the familiar task of mowing the lawn:

> *Now I know, yeah, but it wasn't until I hopped on the lawn mower and then mowed the lawn, and mowed the same spot twice or left a big gap. It was like oh* (P5.1, 131).

Discovering impairments in cognitive functioning were more complicated, because the discovery of limitations in cognitive functioning was hampered by the impaired cognition itself. This was particularly evident when problems with memory and thinking existed. P6 described trying to make sense of impaired memory functions. He clearly articulates confusing and difficult processing of impairments with memory and cognitive function:

> *I think it's improving too but it's partly this bizarre mix of memory stuff that's like - be it new or old stuff, I can get it into my head and lay it down in short term memory. Let's just start with the old stuff first. With the old stuff there's some stuff that I just can't remember and at first I thought it's gone, that's just been wiped. But it's becoming more apparent there's a whole lot of stuff that's not wiped, it's just being able to access it and pull it out in an expedient way. Some things I can just think about it, just a little bit longer than usual and get it. Other things I just don't get it but then 10 minutes later it'll go ping and it'll pop up.*
>
> *But then five minutes after that it'll be gone again. I just think what is going on there? It's just bizarre, it's fascinating but bizarre and the same but not exactly the same, but the same with some stuff that new memory, some stuff I can just - I'll take it on board and I put it in and think I've got to remember that. It's there and it won't be lost during the time* (P6.1, 846).

Discovering limitations with cognitive function seemed to be convoluted, confusing and did not always happen discretely during a single activity. However, in all examples performing everyday activities that were familiar was an essential context for discovery.

Developing an understanding of my altered functional self

Developing an understanding of my altered functional self refers to participants being engaged in a process of learning, where they developed an understanding of how their functional self had altered as a consequence of physical and cognitive limitations. Previously the functional self operated reliably and capability was taken for granted. Participants came to understand that limitations in functioning changed their capacity to be as independent as they had been and the previously capable functional self was altered and now more dependent. A broader perspective of understanding was formed as the effects of limitations were experienced and led to an understanding that encompassed a notion of an altered functional self. The notion of the altered functional self transcended time as understanding was not confined to the immediate point in time of experiencing dysfunction but projected to activities yet to be performed.

As in *discovering functional limitations for myself*, the experience of doing was essential to the process of learning and developing understanding of the altered functional self, however this understanding was gained mostly out of hospital when participants were re-establishing their usual life activities. The experience of performing everyday activities and re-establishing usual life activities with limitations in functioning enabled experiential learning and could be considered the ‘performance context’. Experiential learning also required the home and community environments or ‘environmental context’. Together the ‘performance context’ and ‘environmental context’ comprised a ‘contextual milieu’ for functioning which was necessary for facilitating an understanding of the altered functional self.

Developing an understanding of my altered functional self occurred primarily in two ways, as a result of participants gaining a deeper understanding of specific limitations and experiencing the altered functional self while returning to previous life activities where home and community became a context for understanding the altered functional self.

Gaining a deeper understanding of specific limitations

Participants gained a deeper understanding of specific limitations through a learning process where the participant engaged in some thinking about the limitations they were experiencing and the effect on their functioning. Whereas learning in *‘discovering functional limitations for myself’* happened by chance and seemed accidental in nature, learning which led to a deeper understanding was responsive to experiences and contextual influences and became more intentional in nature.

Thinking about limitations seemed to have a multidirectional focus, where thinking was focused on how an everyday activity had been performed with limitations in functioning, or how it might be performed to accommodate limitations already experienced or whether it would be performed at all. For example, P7 after discovering inconsistency of strength and balance when transferring to the toilet, thought about these limitations and of other activities requiring use of strength and balance, like standing to hang out the washing. Thinking about the effect of limitations experienced previously resulted in P7 deciding not to hang out the washing because she had lost trust in her functional self:

> *Oh no I reckon I could do it; just get up and stand up and hold the line but I said no I don't trust myself because I fell down again you know the other night* (P7.1, 165).

Thinking about the experience of doing enabled development of an understanding of limitations in functioning upon the future performance of usual everyday activities. In addition, the previous understanding of the capacity of functional self was challenged with the altered self now perceived as unreliable and untrustworthy.

Sometimes thinking about limitations and their effect on functioning was not straightforward. Although knowing that she had leg weakness P2 tried to walk between the parallel bars without holding on. After walking only four steps thinking she might fall she "grabbed the bar" (P2.1, 454):

> *One day I thought I was going to be brave. I was going to hold my hands in front of me and go down the bar, ... I took about four steps and realised what I was doing. Immediately I went and grabbed the bar because I realised what I was doing and I didn't want to "phplatt.* [gesturing downwards with hand] (P2.1, 452).

In this circumstance thinking inhibited performance as P2 stated "to me it was the thought that finished it" (P2.1, 457) resulting in the activity not being completed. P2 believed that if she hadn't thought about difficulties in walking, she "would've gone from one end to the other" (P2.1, 459) of the parallel bars. Forming a negative view of the capacity of the functional self prevented future attempts at this kind of activity because P2 "was so disappointed" she "never tried it again" (P2.1, 470).

Thinking about limitations while experiencing the demands of re-establishing usual life activities enabled understanding limitations in functioning within the context of requirements to perform that activity. For example, P2 knew her walking was “very very slow” (P2.1, 84). Thinking about this limitation and having experienced using a walker while shopping and finding it was “getting a bit too hard” (P2.1, 517) to push long distances, led P2 to initiate the purchase of a wheelchair.

P1 continued to experience falling when at home, particularly in the bathroom and he came to understand that his “weak point is to the port” (P1.1, 534) (nautical term for the left). Thinking about limitations with balance and strength plus moving too quickly, within the context of the activity and bathroom layout resulted in a deeper understanding of functioning. P2 determined what contributed to falling and how these specific limitations and the activity could be managed:

> *..that was my fault again I think. I moved too quick and I let go of that bloody bar. I should have still had hold of that bar because I can reach the shower screen with this hand, holding on to that bar. That bar’s really riveted hard to uprights. It’s not going to give way. But I just moved too quick* (P1.1, 596).

Experiencing reoccurrence of specific limitations stimulated thinking which showed a process of learning where it became necessary to understand and determine different ways to perform activities in the future.

Forming an understanding of the combined effects of individual limitations occurred when thinking moved beyond individual limitations and a sense of a whole body alteration formed. Gaining an understanding of the overall effects of functional limitations facilitated forming a notion of an altered functional self. P1 described a list of limitations to his functioning where the sense of the combined effects at the whole body level is beginning to be realised:

> *Well my eyesight’s still not good too and that’s making - that churns me up a bit. When your eyesight’s not good, your hearing is not good, all those things put*

> *together and then you get this dizzy spell, oh Christ it takes a little while to come back to Earth again. You're on cloud nine, you think, Jesus, what was that I was smoking?* (P1.1, 493).

Forming the notion of an altered functional self involved understanding how limitations altered the functional self, and consequently changed perceptions of capability and independence. With the altered functional self perceived as less capable and more dependent. Recognising the need for accepting help and loss of independent functioning demonstrated a deeper understanding of the fundamental effect of change to the functional self. P8 described coming to this understanding when he realised he needed to accept help:

> *Now I've got to sit back and accept a bit of help. That's going to be hard. I'll get there* (P8.1, 404).

Additionally, the future requirement for accepting help was incorporated within the notion formed of altered functional self, where although it will be hard to accept this alteration it was understood as necessary.

Home and community as a context for understanding the altered functional self

Home and community as a context for understanding the altered functional self refers to the influence of the contextual environment when experiencing the altered functional self while re-establishing everyday life activities. While participants mostly looked forward to leaving hospital and this was an important milestone in recovery, leaving hospital was also a triggering event for realising limitations in functioning within a less protected environment. The experiencing of limitations in functioning in the home and community environment after leaving hospital influenced participants' perspectives and understanding in two ways. One way was to provide a comparative environment for performance of the functional self, and the other provided opportunities for experiencing performance in the real living environment. Increased difficulties, becoming aware of dependence and perceiving a greater potential for opportunities to perform everyday activities was reported during first interviews which were conducted, 4 days to 4 weeks after leaving hospital. It seemed the environmental context was necessary for experiential learning which facilitated an understanding of the altered functional self.

Finding it harder to manage at home was indicated by participants with statements such as; “everything’s so hard” (P4.1, 212), “everything takes a lot longer to do” (P4.1, 214), or being “a bit difficult” (P3.1, 362) to get used to “a new system, a different system” (P3.1, L364). P2 compared her functioning against her previous capacity and became “worried” (P2.1, 445) by her experiences once home stating, “I got a bit worried because I'm so slow now” (P2.1, 446). Experiencing dysfunction of the altered functional self in the real living environment where there was comparison between expectations for performance based on previous measures of functional capacity and compared with a changed capacity, informed understanding of an altered functional self.

Experiencing dysfunction in the contextual environment also enabled awareness of increased dependence. For example P3 described experiencing difficulty managing altered bladder and bowel functioning during trial leave in a home environment prior to leaving hospital. Following this experience P3 realised he was dependent upon availability of support and equipment, resulting in determining a need for private supported accommodation arrangements:

> *It couldn’t have been worse quite frankly, from the point of view of my bladder and my bowels. Because I wasn’t in a hospital bed, I couldn’t get - when I was wanting to void my bladder, I couldn’t get the back of the bed up so that I could be in a better position to void my bladder. So that created problems, as did the problem of passing faeces when I was voiding my bladder* (P.3.1, 230).

The learning process of coming to realise alteration to the functional self incorporated knowing functioning was impacted by the environmental context when the environment did not contain elements needed to support changed functioning. In addition, it was sometimes necessary to experience the impact of not coping and requiring more than was available in the contextual environment to understand the nature of changes to the functional self.

The contextual environment enabled the thinking required for understanding of alterations to functioning. For example P3 described how he had not rationalised in his “own mind” (P3.1, 376) and “realised exactly how dependent” (P3.1, 377) he was upon help from others until he left hospital and was living in a supported environment that provided much less help than he had become used to. For another participant the loss of a limb was not fully understood until experienced at home and not being able to walk everywhere:

> *I miss my leg because I’m used to walking around everywhere, now I can’t* (P7.1, 36).

Once home the participant compared functioning with previous independence and capability, realising restrictions and experiencing frustration with having to have someone to help:

> *Because I can’t get out ... I can’t do it and that was the thing I liked doing things for myself* (P7.1, 244)
>
> *I get frustrated when I can’t reach and get the stuff myself. I have to have someone with me and I don’t like it* (P7.1 292)

Experiencing increased difficulties and awareness of dependence after leaving hospital could lead participants to “wondering” if they “did the right thing” (P1.1, 997) by coming home, or questioning whether they were “prepared” (P3.1, 374) enough to manage. Alternatively, as for P8 it led to changing the living environment from a caravan which he found “too hard” (P8.1, 640) after a few days, to living at a friend’s house which was easier to access:

> *Caravan. It's just too hard. I thought it would be easier than it was but it's not* (P8.1, 460).

Thinking in response to experiences in the contextual environment resulted in understanding of an altered functional self and for changed requirements in the environment.

Not being able to perform some life activities, like work (P4.1, P5.1), or driving (P1.1, P4.1, P6.1) was not fully experienced until after leaving hospital. These consequences of the altered functional self were being newly experienced and once out of hospital participants had to think about these “major change”(s) (P6.1, 395) as they had not given “much thought to” (P6.1, 395) them before:

> *I’m buggered. Can’t drive, there’s no public transport down here* (P1.1, L664).
>
> *Just not having a vehicle’s the main part. That’s the hardest part. If you’ve got a vehicle but now you have to sort of arrange because the bus stop’s way over there or it’s just too far* (P4.1, 235).
>
> *I’ve got no work now* (P4.1, 258).
>
> *I mean the only other thing I thought about was and I suppose I don't think this really worried me to an extent or I didn't think about too much until I got home was I can't drive* (P6.1, 377).
>
> *I used to be a keen gardener, I try to get out in the garden or get outside now ..its bending over and stuff like that, the leg just won’t do it* (P4.1, 533).

Incorporating newly experienced changes in capacity to resume usual life activities formed part of understanding an altered functional self.

The contextual environment of home and community was also perceived as providing participants the opportunity for improving function. Some participants found it easier to do exercises and potentially there could be “more improvements at home than there was in hospital” (P6.1, 228). P6 found it “much easier” to set himself up “which make the process of doing the exercises that much easier” (P6.1, 265), and being able to rest whenever he wanted helped with managing cognitive limitations. P1 refused help with cleaning because he perceived cleaning as an opportunity for “exercise” and was something he could do:

> *I don’t want somebody to come in and do the floor. I can do that. To me, that’s exercise* (P1.1, 422)

Understanding what can be performed is an important dimension in an understanding of the altered functional self. The contextual environment of home and community while highlighting alteration in function and awareness of dependence also provided opportunity for performance and for potential improvement:

> *So, yeah, in coming from there to here I don’t think I realised that I’d have to fend for myself as much as I have had to. But that’s been good for me because I can see now that I really have got to knuckle down and just improve in a whole range of areas* (P3.1, 418).

Realising an altered functional self incorporated a positive frame of thinking, with an understanding for future action where learning led to purposive responses.

Sub-Theme 2 – Taking charge to restore my functional self

Taking charge to restore my functional self is the second of three sub-themes in *learning to live with an altered functional self.* ‘Taking charge’ refers to a state or stage reached by participants where they are either in control, or taking control of activities directed towards restoring the functional self. Integral features were being in control by planning and taking purposeful action intended to resolve perceived problems, and learning which progressed to be active and focused. Diagram 4 depicts *Taking charge to restore my functional self,* sub-categories and components

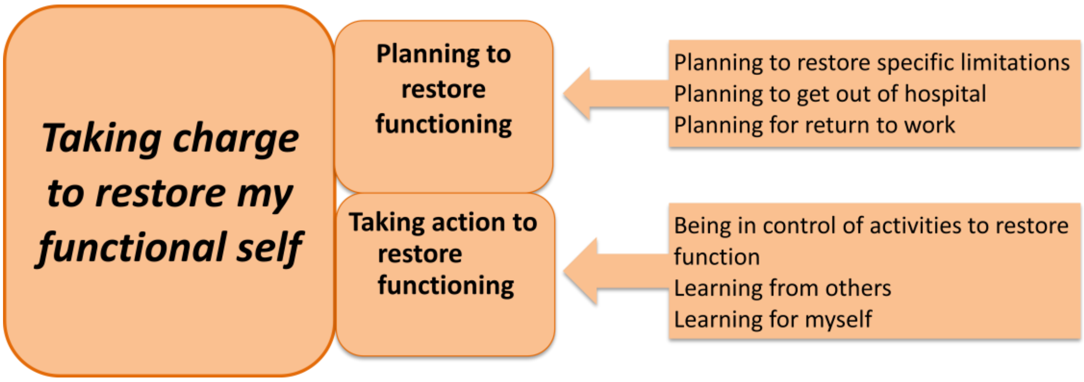


Diagram 4: Sub-theme 2: Taking charge to restore my functional self, sub-categories and components

Comparison of present capabilities with their previous capable functional self provided a direction for action, with motivation to overcome limitations in functioning influenced by participants' desire to be independent and a hope for return to the previous functional self. A pattern of taking responsibility and reliance on self to solve problems was evident.

Learning through experience or experiential learning, incorporated receiving information, using the information, thinking about experiences of using the information received, which led to learning from the experience itself. Learning became adaptive and self directed when new and different ways of doing, or relearning ways of doing occurred under instigation and control of participants to meet their specific needs.

Taking charge to restore my functional self became apparent in the first interviews and occurred concurrently while participants were coming to understand and realise their functional self had changed. Contextual environments of hospital, home and community influenced and enabled experiential learning. However, comparison of functional capability combined with inner concepts of independent functioning were the key stimulus for taking action.

Participants took charge to restore their functional selves by *planning to restore functioning* and by *taking action to restore functioning*.

Planning to restore functioning

Planning to restore functioning refers to planning that was directed towards restoring functioning in response to comparison of present perceived limitations in functioning compared with previous functioning. Planning was intentional and translated into various purposeful actions that participants undertook to improve functioning. Although an understanding of a comparison of functioning was required it seemed that participants did not have to reach a complete understanding of their altered functional selves as planning for restoring functioning commenced while participants were in hospital when they were yet to fully realise their functional selves had changed.

Sometimes planning was clearly stated within examples given by participants when recounting their experiences. On other occasions planning was implicit in their descriptions of actions taken as they were not haphazard but undertaken purposefully and with a clear intent.

When explicit in participants' descriptions during the first interview, planning was directed in three ways: planning to restore specific limitations, planning to get out of hospital and planning for return to work.

Planning to restore specific limitations

On finding they were less capable than before, participants made plans to correct perceived problems. For example, P3 perceived an inability to walk as a problem, not just because this is a basic physical function but also because he previously led a vigorous and active life, jogging, hiking and bike riding. He was motivated strongly to regain these abilities which were translated into a plan “to inject exercises” to help “overcome that problem” (P3.1, 96):

> *I, of course, couldn’t walk when I came out of the coma and really wanted to walk because my life without being able to walk and jog wouldn’t be a life I would look forward to. So for that reason, I sought to inject exercises that helped me to overcome that problem* (P3.1, 96).

Experiencing specific limitations in an environment where the alteration in performance capability became apparent and the demand for performance was greater than the capacity, contributed to planning. Plans made addressed the shortfall perceived between what the participant could do and what they perceived they needed to be able to do. P3 realised his difficulties with walking and loss of function of one upper limb increased his dependence in performing everyday activities, like walking to the toilet, showering, dressing and transferring. He planned to correct these problems in order “to come up to standard” (P3.1, 397) by concentrating his efforts on walking:

> *Oh it made me more - it made me concentrate on what I need to do to come up to standard*. [daughter’s name] *and I have talked - that’s why she’s going to come up here a few days and take me out walking. That’s why I’ve talked to* [daughter’s name] *and* [HCP’s name] *about how much walking during the day I should do* (P3.1, 396).

Planning included determining strategies to address perceived problems of dependence, namely increased walking practice and included asking for help from others to carry out planning. Thinking about and planning to correct problems experienced seemed to be influenced by perceptions of importance of these problems to the individual as well as the comparison of performance capability.

Sometimes limitations in functioning were perceived as “challenges” (P6.1, 793) to be overcome. P6 described planning to increase his reading capacity with a time frame to achieve a specific goal. He thought about current performance and his planning incorporated understanding of his limitations of being able to read “up to page 4” (P6.1, 793) of a children’s book and only reading about a page at a time due to reduced cognitive endurance:

> *I thought that will be one of my challenges to try and read. So I can read - I'm up to page 4 or something like that. I can read about a page and then my brain sort of goes okay, take some time off. But anyway by the end of the month I want to work my way through with the level that* [name of child] *is at now* (P6.1, 793).

P6 identified stages in his planning and an initial modified goal to work through to “the level” of his primary school aged child based upon his understanding of his performance capability. Although, he could be daunted by levels of literacy well below his previous capability (having university qualifications), P6s’ plan incorporated positive views of a challenge to be overcome. With a staged plan of action which initially aimed for improvement rather than return to the previous capacity of functioning.

Having a future perspective of a goal in mind seemed integral to planning to restore functioning and having a time frame added focus to the actions to be undertaken. P8’s planning allowed for a longer time period of two months to improve walking strength and balance so that he would be “walking around...without crutches and walking sticks”(P8.1, 522) using his prosthesis only. He described this as his “next goal” (P8.1, 523), implying there had been previous goals and that he had an overall plan. In addition, he linked taking purposeful and self initiated action as necessary to the plan, when stating that he needed to “get up and do it” (P8.1, 524).

Planning to get out of hospital

Strong and multiple expressions of the desire to “get out” of hospital (P2.1, 110; P3.1, 315; P5.1, 82; P8.1, 317) were made by most participants. Actions to restore functioning undertaken while in hospital seemed to be directed towards achieving this. P5 was motivated to improve as “fast” as he could and planning directed actions undertaken to “fast track” his discharge:

> *I just wanted to get the hell out of there. Fast track* (P5.1, 82).

P8 described determining timing of his discharge date once his wound was healed so that he would have time for gait training with his prosthesis and other actions needed to leave hospital:

> *I wanted to get out. Nothing was going to - I aimed for a date about six weeks earlier and that was last week. I overshot by one day* (P8.1, 317)

Planning included purchasing a different car to be converted and licence changes during the six weeks he gave to be “ready” (P8.1, 328) for leaving hospital.

Planning to get out of hospital was not always straightforward. For example, P3’s desire to get out of hospital led him to plan how he would assist the process by providing overly positive reports on certain aspects of his functioning:

> *I think I really just wanted to get out of the hospital. I wanted to make out that I was doing very well in all of these areas, so that I’d be given a big tick from the nurses who have made - and doctor - who made that judgement. It’s as simple as that* (P3.1, 349).

Planning for returning to work

Participants who had been employed previously engaged in planning for return to paid or unpaid work. As participants had recently left hospital at the time of first interviews, the planning described took the form of considering options or making more tentative plans for returning to work in modified ways. While plans to restore specific limitations and to get out of hospital were more focussed on individual limitations or on problems to correct, planning for return to work differed and took into account needs at the level of the altered functional self. Return to work involved resuming an important life activity, and therefore restoring functioning considered job requirements, perceived capability and potential of the altered functional self.

Planning for return to work involved acknowledging limitations in functioning that could preclude return to previous work or may require performing a job differently. For example P4 realised that she was unable to return to her previous work due to physical limitations in strength and endurance with walking and pain resulting from lengthy standing. As her previous employment was an outdoor physically demanding role, planning involved thinking of options for part-time, volunteer or unpaid work in the same setting with limitations to hours. This allowed for uncertainty about being able to commit to the previous job requirements:

> *I've been looking to do some part time in a month or two when I settle down a bit, or try and get some volunteer work just so that - if I can't turn up or if I'm having a bad day or something like that* (P4.1, 258).

Options for changing the type of employment were also considered and included understanding of functional limitations:

> *I think I could probably do a bit of bar work wouldn't be able to stand up too long see, stand for a little bit of time, then sit down, when I sit down I've got to keep moving, got to get up, get off my backside a bit* (P4.1, 527).

When planning for work P4 considered that her future capacity was still unknown as she had "only been out a week or so" (P4.1, 263) and she wanted to wait and "see what happens after about a month" (P4.1, 263).

P5 made plans for return to work but to a different job as he felt his previous employment was "too stressful" (P5.1, L 204). Anticipating future capacity for return to work but acknowledging limitations in an already stressful job that was "pretty full on" (P5.1, 212) resulted in planning for different employment:

> *I'll be back at work in about three weeks' time. I've got a guy who wants me to go and work for him* (P5.1, 393).

When planning for return to work, future possibilities of functional capability were not always certain and it seemed that planning included elements of hope and allowed for differing eventualities. For example, P8 considered options for education and a new vocation as he could no longer could perform essential physical aspects of his previous employment:

> *As I said I'm getting an education. Going to make enquiries about becoming a counsellor. I don't know how to do that yet but I'll find out. Go to college or whatever you have to do. Eventually get off the pension and earn my own living. I'm too young to sit down ... Too young to not work* (P8.1, 417).

Recognising limitations brought about by the health event and having time to think about these limitations and experiences when in hospital resulted in P8 making short and longer term plans for a different vocation that would require developing new skills.

Taking action to restore functioning

Taking action to restore functioning refers to purposeful actions that were undertaken to restore physical and cognitive abilities to previous levels of functional capability. Comparing limitations in functioning with previous abilities and realising the functional self had altered, resulted in actions motivated by the wish for return of previous functional capacity and for return of independence.

Integral within taking action were factors of control and responsibility for making decisions. Thinking about present performance and experience of limitations and comparing with past capable performance, resulted in decisions for taking action. Participants were in control of intentional actions to restore functioning and determined how and when these actions would occur. Continuation of learning was apparent in how actions were undertaken and in the utilisation of information received, thought about and acted upon.

There were three aspects to *taking action to restore functioning* these were; when participants were in control of activities to restore functioning, when learning from others and when learning for themselves.

Being in control of activities to restore functioning

Participants reported during first interviews various forms of being in control of activities that were intended to restore functioning. These were; by making decisions on how exercises perceived as beneficial would occur when in hospital, continuing exercises when at home, experimenting and pushing themselves.

Participants determined aspects of activities they found beneficial and those less so. Choices were made, preferences communicated and then followed through on those decisions with action. For example, P1 decided that in order to get the most benefit from exercise to increase strength, balance and endurance it was better for him to practice walking with his frame on the rehabilitation ward than to travel to therapy areas. Travel took time, involving use of a mini bus to go to another building on the hospital campus which had equipment not suitable for his circumstances. P3 "couldn't use" (P3.1, 258) specialised equipment due to a hip problem that was unrelated to his health event and he responded by taking action to inform the health care professional (HCP) his preferences and reasons for decision:

> ..*all he could give me was the parallel bars, because I couldn't use my other leg on his exercise machines. He's got dozens of machines there to boggle your brain… I couldn't use them, because I'd have to use two legs. I couldn't use two legs. So I said* [name of HCP] *this is ridiculous, I'm coming over on this bus and just walking the parallel bars, I walk around the ward. I've got this* [referring to walking frame], *that's a bloody sight bigger than the parallel bars*. (P1.1, 259).

P1 also described initiating going for walks around the rehabilitation ward area with help from nurses. Being in control of the activity included determining how far he would walk, whether a rest was needed along the way and communicating these decisions:

> *The nurses didn't mind, I said, come on, we'll go for a walk. Yeah, righto. It was a bloody unanimous decision, let's go, because I'd have a talk and… I could get back to the bed, I was buggered. I needed to sit down by the time I got back. Or on the way back I'd think, no hold on I want to sit down for a while so I'd go into the TV room. That's why I reckon it's a good idea that they haven't got television sets there* (P1.1, 955).

Performing extra or frequent exercises in the hope that this would improve functioning was a particular form of being in control. For example, P4 described doing exercises when in hospital "all day from the time" of getting "up to the time" of going "to bed" (P4.1, 535) and purchasing her own "exercise ball" (P4.1, 254) to keep on with exercises when at home. P3 "sought to inject exercises" (P3.1, 99) to improve walking when in hospital and once out of hospital continued doing "extra walking" (P3.1, 289). P7 also mentioned frequent exercise as a something incorporated into her daily activity when at home.

> *I do that all the time on my bed, you know, exercise.*
> *Even if it's only 10, 15 minutes and then I'm up and about* (P7.1, 70).

P5 deliberately extended the time and frequency he performed exercises when in hospital to "fast track" discharge from hospital (P5.1, 474):

> *Oh, well* [name of HCP] *at rehab, he'd say 15 minutes on the exer-cycle. Do this, do this, do this and then you can* [---] *off. Well I'd do that twice, then go to bed, come back and then do it again. He'd just say what are you doing? Fast track, mate. I want to get out of here. It's all about fitness, so bring it on* (P5.1, 474).
>
> *On the weekends and that, because he wasn't on the weekends, I'd just go and do it two or three times on the weekend. On a Saturday and Sunday* (P5.1, 483).

In the week before leaving hospital, P6 took control and used exercise and dining areas on the rehabilitation ward:

> *I mean towards the end, I think the last week I was starting to do stuff like - I would take the stuff that I was working on and either go to the exercise room on level 4 or the dining area because they had tables there and I'd do stuff there* (P6.1, 258).

Exercises commenced in hospital and continued at home seemed to demonstrate a progression of increasing control and occurred as capacity for being responsible for taking action also improved. There seemed to be a concurrent or interrelated development of understanding of limitations while trying to overcome those limitations. For example, P6 described improvements in “memory” and “ability to organise” (P6.1, 232) himself, enabling continuation of exercises once home, where he could “find ways to” exercise his “body” “without using actual exercise equipment” (P6.1, 238) and continued “speech therapy” “under [his] own steam” (P6.1, 251). There was a requirement for improvement in cognitive capacity to enable making these plans and for control of the activities.

Being in control and making decisions to undertake activities that were experimental or involved taking risks was another way some participants took action to restore functioning. For example, P4 attempted a physically challenging activity while on trial leave that had unintended results. Expecting that riding her own push bike would be similar to the exercise bike in hospital she decided to pump up the tyres and go for a ride. Unfortunately the tyres were flat, and after walking the bike to the nearest service station where the pump was out of order, P4 was forced to walk the bike back home again. Walking back and pushing the bike with limitations in lower limb strength required “three stops” (P4.1, 546) along the way and caused back pain and exhaustion:

> *I didn’t even ride it had to push it back, got in here, laid down there, puffing.. said give us a drink give us a drink* (P4.1, 550).

Closely aligned with experimenting and taking risks were features of pushing harder and not giving up. As P4 planned to “give it a try” (P4.11, 539) again once home even though the experience of attempting to bike ride had been physically challenging and capability was uncertain.

Pushing harder and trying again seemed to indicate a strong motivation to achieve change. For example, P1 described walking around at home “as much as” (P1.1, 732) he could, to “push a little bit harder” (P1.1, 733). P3 described becoming “a bit gung-ho” (P3.1, 401) requesting to walk the stairs when walking on flat surfaces was very difficult for him, requiring support of one person and a walking aid. Deciding to undertake this activity, choosing a particular HCP who he perceived as strong enough to support him through the activity and who “put a bit of steel into me so that I could walk all the way to the top” (P4.1, 410), was evidence of being in control.

The experience of pushing to extend physical functioning, while challenging and could be seen as risky, did not deter participants and was perceived as having potential for achieving an improvement in functioning. For P3 the experience of achievement in circumstances of difficulty “was very important for [his] confidence” (P3.1, 416) and influenced motivation to keep trying.

Learning from others

Participants utilised information received from others to assist with improving functioning and performance of some activities. Learning from others involved receiving information, using that information and applying it to differing situations where participants could test and confirm its relevance. Application of information in hospital and once out of hospital resulted in participants modifying through experience how they performed certain activities. For example, P1 who experienced limitations of balance, strength and dizziness if he moved too fast resulting in falls, described being “taught” (P1.1, 383) to take things “slowly, slowly” and “take it easy, settle down” by “not one, but lots of people” (P1.1, 384) when in hospital. Having “thought ...there must be something in this” (P1.1, 387) information he modified how he had been mobilising:

> *So I did exactly that, even in the hospital in the finish I was walking slower. I was doing things slower* (P1.1, 388).

Later when he was home P1 applied this information to slightly different situations, for example when bending over to pick up objects and found that the strategy continued to work for him.

> *I was on my way to the cup I know that, but why did I knock the bloody thing over for Christ’s sake? You’ve only got to pick up a cup. So then woo, woo, hold the boat. There’s a cup, I pick up the cup. That attitude, you know? It’s working.* [Demonstrates slowly picking up the cup] (P1.1, 390).

P3 described learning from others when in hospital, strategies that would help with managing his bladder and bowel, and putting those strategies into practice he found “a tremendous aid” (P3.1, 213) in improving function which gave him “a lot of confidence to be able to know that I can do that” (P3.1, 216). Transforming information to experience, allowed the confirmation of the information as being helpful and gave control for taking action to achieve continence and reliability of bowel functioning. For P3 “knowing what you’re telling me is actually working and making a difference” (P3.1, 515) gave confidence for self management. Learning about bowel functioning from others and confidence gained through experience of the responses to strategies suggested led to P4 experimenting “with some of those things which was good” (P3.1, 529).

Learning for myself

Some participants initiated learning activities for themselves with the intent to learn new ways, different ways or to relearn ways of doing. In learning for myself, participants were conscious of this purpose when undertaking self learning activities that were aimed at restoring functioning. Inherent within self learning were the elements of being in control and self-determination. For example, P2 described how she “taught” (P4.1, 628) herself “to walk with the walker” by going to the toilet without assistance and without telling anyone:

> *while I was in the hospital - five o'clock in the morning I had to go to the loo. That's when I taught myself to walk with the walker. But nobody knew, except my bed mate. I never woke her up. I got sprung. I went to the loo one night and said ‘oh, what a relief.’ Normally I was quiet. ‘What are you doing?’-‘ I'm having a wee’. –‘Since when did you start going to the toilet on your own?’- ‘I'm a big girl, love. I can go to the toilet on my own, and pull down my pants and pull them back up* (P2.1, 627).

P2 felt strongly about being independent and liked “being in charge” (P2.1, 356). However, her aim wasn’t simply to undertake this activity by herself, her intent was also to teach herself how to mobilise with limitations in function and the actions to achieve this were undertaken deliberately.

P6 defined his situation as a “unique and a very unusual learning experience” (P6.1, 501), recognising that he was “going to have to do something slightly different” (P6.1, 496) to restore cognitive limitations than for physical limitations. Experimenting with different strategies contributed to the gaining of an understanding of his limitations and demonstrated self initiated learning in trying to find ways to improve memory and self organisation:

> *I have started. I mean that's, I suppose it's - I have started thinking about and I'm not sure what the right strategy is. But at least one of the options would be this, for those things that sort of pop up occasionally and then they're lost whether I write them down because that certainly does seem to help. For some of those things, if I write them down I've got a list I can look at* (P6.1, 888).

Sometimes learning for myself progressed from learning from others when the information received became the basis for participants developing their own ways for improving functioning. Exercises from the rehabilitation setting carried through to the home setting still required the individual to “explore options” (P6.1, 936) and find the most suitable for them:

> *..it will be interesting to see in the longer term what sort of stuff has worked. I know at least some of it is down to me that sort of stuff to explore those solutions because there might be a range of solutions. But you the user have to find the one that suits you best* (P6.1, 928).

Determining strategies and ways of managing altered functioning based upon information received and then adapted to meet individual requirements displayed a level of self learning where understanding, experience and taking charge combined. This was also illustrated when P3 used information received about bowel functioning, and gained in depth knowledge of the effects of aperients through experiences of bodily responses to the strategies provided. The combination of theoretical and experiential knowledge resulted in being able to develop a new individualised management regime. Being empowered to be in control also allowed the feeling of being in control over functional aspects that had previously been difficult to manage:

> *I think with your knowledge passed on to me, I was able to see why Coloxyl Senna and Movicol could assist me in developing this new regime. It’s certainly worked. But more importantly what it did do, if I was missing a day, I was able to - obviously you didn’t want me coming to you every day saying look I missed. But what I was able to do was calculate in my own mind if I should take an extra Movicol or miss out on a Movicol if my faeces were becoming too loose. So yeah it gave me control, greater control, over what I was doing that I never had before* (P3.1, 191).

Being in control of learning ways of doing and of solving problems was also expressed emphatically, where responsibility belonged to the individual and not others. For example, P5 expressed that he usually found “a way to do it” (P5.1, 620) himself:

> *I'll work it out how to do it. Might take me a bit longer to do something, but I'll get there. I'll work it out* (P5.1, 627).

Taking action to restore the functional self incorporated being in control of a range of activities and active adaptive learning experiences some of which originated from others and some of which were self initiated.

Sub-Theme 3 - Taking charge of my changed situation

Taking charge of my changed situation is the third of the three sub-themes in *learning to live with an altered functional self.* In this theme there is a significant shift in the perspective of participants that had occurred over time as this perspective was evident in second interviews, and in the first interview of one participant who had been in hospital for longer than 12 months. Diagram 5 depicts *Taking charge of my changed situation* sub-categories and components.

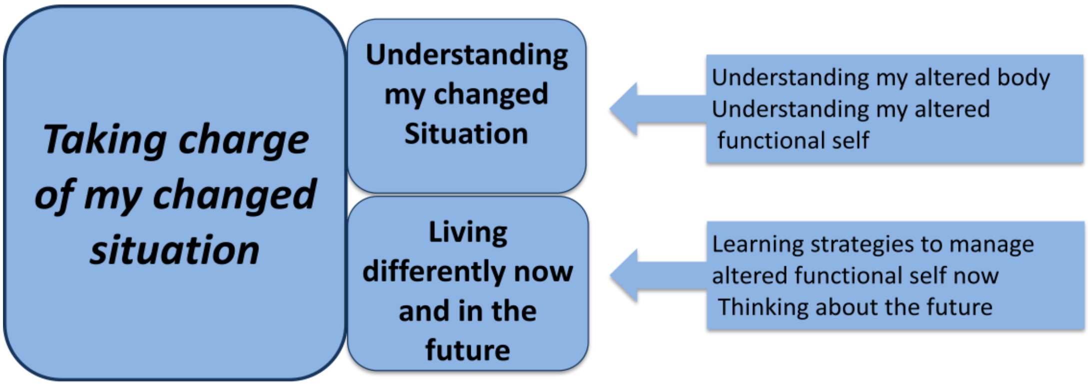


Diagram 5: Sub-theme 3: Taking charge of my changed situation, sub-categories and Components

Taking charge of my changed situation refers to the changed focus of getting on with life demands with the altered functional self by learning different ways of performing every day and usual life activities. Participants became knowledgeable and expert about their progression in functioning over time, developed strategies for managing limitations and made the most of capabilities. Thinking also extended to considering future alternatives.

Self awareness of limitations and capability derived over time led to an understanding of the multifaceted and complex recovery pattern experienced. This understanding led to self directed responses that were problem solving and adaptive, promoting the continued participation in life pursuits. Integral were participants being in charge of learning processes and adaptive living, including notions of the potential for continued improvement as processes of recovery were not definitive at the time of these interviews.

In order for participants to take charge of their changed situation they had gained and understanding of their changed situation and were learning to live differently.

Understanding my changed situation

Understanding my changed situation refers to the understanding gained of the changed situation lived by participants. This understanding was derived over time through the contextual elements of experiencing functional capacity when performing everyday activities at home and in the community. Experiencing functional capacity involved the experience of improvements in functional limitations, enabling performance, and the experience of limitations in functioning that made performance difficult. Participants came to know characteristics of their functional capacity, as the amalgamation of both limitation and capability experienced when performing everyday activities and this knowledge was specific to circumstances of the individual.

To understand the changed situation participants seemed to have incorporated experiences of their responses to restorative actions; experience of the performance of the altered functional self; and knowledge of functional capacity gained from performing everyday activities regularly over many weeks into an accumulated and combined knowledge. The accumulated knowledge of performance or capacity of the functional self derived over time was understood not only at the level of the self but was also understood from a broader perspective of the person's changed or changing situation.

Gaining understanding of a changed situation was described by participants in the second interviews after being out of hospital for some months.

Two perspectives contributed to the understanding of the changed situation lived by participants these were; understanding what happened to altered body functioning over time; and understanding what happened to altered functional self over time. The perspective most described was experiencing the altered functional self over time, within the context of performing every day activities, and re-establishing previous roles and life activities.

Understanding my altered body

With the passage of time participants gained an understanding of improvements, deterioration and new developments in functioning of the altered body. Consideration of bodily responses to actions taken to restore functioning and of responses that occurred over time informed the conclusions and evaluations of functioning and these evaluations indicated an understanding of the altered body. While improvements in functioning were reported, no participants reported a return to the functional capacity experienced prior to their health event. More commonly participants described a combination of improvements in some areas of functioning and non improvement or deterioration in others. This mix of responses highlighted the complexity in recovery and understanding the altered body involved grasping the different facets of functioning that had developed over time.

An example of coming to know the subtleties of the altered body can be found in how P1described improvement in walking inside, while continuing to have difficulty walking outside on soft grass. The evaluation of performance included a combination of functional variables within the activity of walking. There was the understanding when walking longer distance inside he needed to walk near the wall, improvement was recognised by acknowledging what he couldn't do before but was now able to do and limitations in not being able to walk outside in longer grass. This demonstrated an understanding of the multifaceted nature of the functioning of the altered body:

> *I can now get up and I can walk into the kitchen now. I could walk down to my bedroom now but I'd make sure I'm near the wall. I couldn't do that before but I can't use the push, I can't walk around the yard with this* [referring to wheeled walker] *because the wheels – if the wheels were bigger it would be good but there are little tufts of grass that I'm battling pushing this* (P1.2, 275).

Understanding the multifaceted aspects of altered body was applied to circumstances where there was a mix of responses across different body functions. For example P3's evaluation of his functioning over time, included his perception of deterioration in walking and an improvement in bowel function with the return of sensation for defecation. Deterioration in walking was perceived to be due to a lack of opportunity to practice and required more restorative action, however improved bowel functioning was due to a mix of learned self management techniques and recovery of neural pathways and neural functioning which had occurred with the passing of time. P3 indicated an understanding of his situation which included aspects of functioning that were difficult to change and not always within his control.

A different aspect to the complexity in understanding the altered body was when performance requirements impacted upon the experience of functioning exacerbating or causing other limitations. For example P4 described improvement in walking and a corresponding increase in the experience of back pain, requiring medication, the occurrence of pain linked to doing more exercise. Knowing the altered body involved a complicated amalgamation of differing aspects of functioning. For P4 this included an evaluation of improvement in leg strength but not restored to previous levels of capacity and an increase in back pain if exercised too much, however exercise was deemed necessary to improve function and strength, the situation characterised by P4 as a "catch 22"(P4.2, 159):

> *that joint there is real painful all the time, so I've been taking Tramadol and I've got one of those medicine balls over at* [location removed for anonymity], *those big balls and I've been doing the rolling over and everything that I was doing at the rehab centre, but the more I do the worse the back pain gets. But if I don't do anything, he sort of says, it's off on a part nerve, so it's like a catch 22* (P4.2, 154).
>
> *It worse, because I'm doing - I'm walking more, because you've got to get about* (P4.2, 167).

New or developing elements to the experience of body functioning could occur over time and these elements were incorporated into the understanding of the altered body. For P4 this was increasing pain with increasing leg strength and exercise, for P7 pain became a constant which had not been experienced earlier and had developed over time. Scattered throughout P7's account during the second interview were small but telling references to pain becoming a continuous and overwhelming experience:

> *It's hurting. Yes, it's hurting* (P7.2, 12).
> *Nothing helps to stop it* (P7.2, 14).
> *It's getting worse. The phantom…* (P7.2, 20).
> *Yes, worse. That's why I have to keep lying down all of the time* (P7.2, 22).
> *All day, every day. It's the only way I can stop that pain* (P7.2, 62).

The experience of difficulty in one area of functioning sometimes coloured perceptions of the altered body, with other health issues also influencing perceptions. For example, P1 had a chronic hip joint complaint which caused pain and discomfort and affected his ability to walk, compounding the effects of the health event that had required rehabilitation. P1 felt overall he hadn't improved stating "if there is any difference I'm going backwards" (P1.2, 112) reporting he wasn't "getting any better with my walking" (P1.2, 116). This perception was largely due to the complications brought about by his hip complaint as he also described examples of improvements in his mobility.

Learning and coming to know altered body functioning required opportunity within the home and community environments to undertake everyday activities in different ways, with time to measure and monitor responses. Conclusions of improvement often involved some condition or qualification which could be seen as a progress towards an end that had not yet been reached. Participants' evaluation of performance came about over time with experience, yet still involved an unknown future outcome. Understanding the altered body therefore included the notion of potential for improvement, multifaceted variables of limitation and capability of functioning and in some instances included new or developing issues.

Understanding my altered functional self

With passage of time participants gained an understanding of the capacity of functional self through repeated experiences of performing everyday activities and re-establishing usual life activities. Learning about the capacity of the functional self over time revealed limitations and capability, as well as providing opportunity for progression or improvement. Similarly to understanding the altered body there was often a mix of proficiency when undertaking every day activities due to the multifaceted nature of recovery of functioning. Understanding functional capacity from a broader perspective of the functional self resulted in understanding changes to the participant's situation.

The importance of the passage of time and opportunity to practice activities in real conditions was evident in some participants' conclusions and evaluations of the altered functional self. For exampleP2 described a progression of understanding the altered self that changed from when first left hospital and "wasn't terribly happy" (P2.2, 146) and was "trying to get back into action" (P2.2, 147) to describing improvements over time resulting in being able to "now" do her "own laundry" (P2.2, 149) and cooking. Understanding the altered functional self included the knowledge of increased capability in carrying out activities combined with remaining limitations as P2 continued to be "just a bit slow" (P2.2, 151) when undertaking these activities. Experience and knowledge of proficiency of the functional self led to an understanding of the changed situation which was not always definitive. P2 expressed this understanding when she described herself as "not quite" (P2.2, 155) what she was before and uncertainty was indicated by having "doubts" (P2.2, 354) about her situation: *I'm finally getting in the swing of - I do my own laundry. I cook for myself. But I have doubts* (P2.2, 363).

Participants became expert about their functional selves because of the experience of living their changed situation and described in detail how they performed activities, including which aspects they performed for themselves and where they needed help. This self awareness was derived from repeated experiences over time of functional capability, of limitations in functioning and factors within the environment. P1 described his understanding of altered functional self gained where some improvements in leg strength and balance encouraged a return to cooking activities, but experiences highlighted difficulties which had not resolved. The requirements of the activity combining the need for balance, walking and hand coordination were beyond his capacity and understanding the changed situation came with knowing help was needed from his house mate:

> *Now for instance two hands, I'm buggered if I take - well* [name of house mate] *helped me twice because I'm stupid, taken the bacon dish out of the oven, bend down there to pick it up and it was bloody red hot. You know you've just finished baking something, you've got it with two hands and I don't know what it is in your body when both hands are immobile, you're even more vulnerable to losing your balance or not being able to do something. If you can let one hand go, for some reason or other, you're a little bit better off.*
> *When both hands are occupied at the same time it's bloody terrible and I've nearly dropped what I've been trying to carry just from the oven onto the bench and walking three feet. I couldn't, I could hardly walk.* [name] *would be there.* [name] *and he came over and he'd grab it and honestly I think if he hadn't of been there I would have dropped it. I wouldn't have been able to stop myself from dropping it* (P1.2, 682).

Expert knowledge of the functional self included inherent features of control, because knowing specific details of capability in performance gave a pattern to the continued performance of the activity. The knowing of and determining this pattern equated to control of the activity. For example, P3's detailed description of the routine established for walking to the shower, which parts of the body he was able to wash and dry and negotiated aspects carried out by paid carers described a pattern for performance of this activity which was developed over time. The pattern incorporated progressive improvements in functioning where there was clear delineation between independence and dependence within the activity:

> *I've walked to the bathroom by myself about six times and can certainly walk there but it's good to have a commode over the toilet and now I can take myself from the toilet to under the shower - I don't need assistance with that. I put the shower on and I can wash myself. Someone comes in and sometimes just washes my back and I can - I've come to an agreement with the carers that I dry myself from head down to my knees and half way down my legs. I do it around my testicles and so on and they just dry my back and so on* (P3.2, 261).

Knowledge through practice and self determination in the performance of the activity led to understanding and control of the changed situation.

Participants described experiences of variable performance of the functional self when returning to life activities such as shopping, driving, use of public and private transport and return to work. Differences in mobility, strength, bowel functioning, concentration and coping with stress affected how these activities were performed and often more than one area of functioning impacted within an activity. Learning in these situations resulted in responses by participants that enabled continued performance or sometimes provided information for taking different directions. It seemed that challenges within these activities were required to reveal the nature of the difficulties, yet these challenges didn’t appear to deter participants from continuing to problem solve and participate. For example P4 found walking longer distances to go shopping at a large shopping centre resulted in leg weakness, where she was forced to sit and rest. The activity of shopping was further complicated by unpredictable bowel functioning resulting in having to leave the shopping trolley partly filled and to go home. Later P4 described continuing to use public transport to go shopping, with manipulation of diet and timing of medication to regulate bowels to prevent the need for the toilet when it wasn’t available during travel. P5 returned to work, to a different job thinking that his previous role was too demanding. However, experience of limitations in a different role with new skills to be learned became more challenging than anticipated. Undaunted by this experience P5 negotiated a return to his previous familiar employer but with the job modified, with a plan to try again in the future:

> *it was all new. So it was just all wow, too overwhelmingly I guess for the head. I'll go back to the push bike with the training wheels on it and make it easy* (P5.2, 394).
>
> *Now my head's where it is and maybe in another six months I could go back and have another go at that job and probably be able to pick it up and do it. But to start with it was just too draining* (P5.2, 387).

The contextual milieu of experiencing performance of the altered functional self when undertaking usual life activities in the community environment provided a platform for a progression in performance over time. Participants aspired to accomplish these activities as they represented important elements in the fabric of their daily life. Participants came to know how their functional selves operated in these situations and although difficulties were encountered, adjustments were made to enable continued participation. These adjustments are further described in the next section.

Living differently now and in the future

Living differently now and in the future refers to a range of productive and adaptive responses by participants to experiences over time of altered functional self when undertaking everyday and usual life activities. The focus of these responses was to ease difficulties in functional performance, enabling participation in daily life and formed part of a continuing learning process. Participant's utilised learning gained as described in *understanding my changed situation* and over time through thinking and doing developed different ways of undertaking activities.

Learning to live differently now and in the future was demonstrated in two ways by participants, through descriptions of strategies learned to manage the altered functional self and by thinking about future which incorporated an understanding of changes to their situation. Descriptions of learning strategies and thinking for the future were contained in the second interviews for all participants and for one participant in the first interview who had been in hospital for a prolonged time, over 12 months.

Learning strategies to manage altered functional self

Participants learned through experiences and developed a range of strategies that catered to their specific situations which minimised or prevented difficulties when undertaking everyday and usual life activities. Of the strategies described most seemed to have originated through the thinking and experience of participants and as such were self determined strategies to minimise the impact of alterations in functioning. Some strategies were continued from when in hospital and developed or modified with experiences of progression in functional performance over time. Strategies learned by participants could be divided in to two main groupings, namely thinking strategies and doing or action related strategies. While strategies were individualised to participants circumstances a few were commonly adopted by most participants.

Thinking about the details of performing an activity beforehand was a frequently reported strategy. Participants learned that thinking before helped with ensuring the activity was carried out safely and effectively as they had learned some activities could no longer occur spontaneously or automatically:

> *Think about everything. Think about it before you do it. Have you done everything before you do that? A few times I've gone out, taken everything off and sat in the car - I forgot something. Go back into the house and get it. I've got to think about it* (P8.1, 504).

> *If I think I can't tackle it, I'll sit and think about it. I'm serious. I'll sit and think about it. No, that way would be better and I'll try that way* (P2.2, 402).

Timing of thinking occurred just before the activity or sometimes participants would lie awake at night thinking of how they would carry out specific activities the next day:

> *I go to bed at night and I think, God, what am I going to do tomorrow? I'm already planning, I just can't sleep and I lie there at night and I think* (P4.2, 301).

Thinking before and during the night sometimes resulted in not performing activities if deemed doubtful. Having time to work out ways of doing demonstrated how participants took control and were in charge of problem solving difficulties experienced with altered functioning:

> *I've had to think seriously. Will I get from point A to point B this way? ... There's an old, old, saying. When in doubt, don't. I've been telling myself that all night. I need, no, a bit dicey, now how the hell can I do that? ... I honestly think when it is a bit dicey, I've worked it out. I've got all the time ... I do like to think I'm intelligent that way* (P2.2, 409).

Other types of thinking strategies occurred less commonly and related to specific circumstance of the individual. For example avoidance of some activities that were known to exacerbate limitations in functioning was a learned thinking strategy for P1, who over time continued to experience dizziness so learned to avoid certain movements and situations. Thinking during and after unexpected difficulties encountered in an activity produced different strategies to solve problems enabling management of the situation in the present and future. P3 experienced the need for creative thinking when encountering an unexpected problem with using a public toilet, which was compounded by his inability to easily transfer back to his electric wheelchair and use another toilet.

Thinking strategies to manage cognitive difficulties were more complex when thinking resulted in modifying how some aspects of the activity were perceived and involved changing the thinking about situations encountered. For example P5 sought to reduce stress levels in certain situations so modified his thinking to this end. By not caring as much about demanding aspects of the activity and choosing to change his usual responses he was able to reduce stress when not performing the activity to the degree he had been capable previously:

> *I just don't care anymore. The boss knows that I don't care, if it doesn't get done today, I don't care, it will get done tomorrow. I can't afford to stress out about it* (P5.2, 82).

> *I just don't care, only because I can't afford to care, mentally and physically I can't afford to care* (P5.2, 116).

> *I still try and make it happen but if it doesn't happen well it doesn't matter* (P5.2, 125).

Thinking strategies to manage altered functioning involved thinking about the detail of the activity, about contextual factors within which the activity occurred and the manipulation of these factors. Learning processes were evident with participants logically thinking through the sequence of steps, planning, reviewing and thinking about mistakes and reflecting on how it could be done better in the future.

Participants described a range of action related strategies developed in response to alterations in functioning and exemplified the translation of thinking into doing. Experiences over time of the altered functional self and thinking about these experiences resulted in the intentional adoption of strategies designed to enable continued performance of a range of activities. One frequently mentioned strategy was the need to slow down and take time. This was not just a description of a functional consequence or limitation but took the form of a learned and chosen way of doing and became an adaptive strategy:

> *I do it when I'm ready. I gear up to it. Going along slowly* (P7.2, 104).

> *what I found out the last week, giving myself enough time to do everything. Just can't get up and walk out and get in the car and go. That's just the biggest thing. I've just got to give myself time. Where I was this time 18 months ago I was into fast forward. Now I've got to be slow* (P8.1, 500).

Other strategies related to doing activities in a different way to promote independence and compensate for limitations and as such were individualised to participants' specific circumstances. For example P7 found a way to hang out the washing by using a different line at a height she could reach and hold onto:

> *I stand up to that one and I hold the line. I do that and I feel proud of myself when I'm hanging my clothes up* (P7.2, 99).

Strategies were developed because the importance of being able to complete the activity was greater than how it was performed. Rearranging the environment in which activities were performed was another variation of action related strategies. P2 kept her phone nearby as she found that limitations in walking slowed her down and simple adjustments in practice minimised the effect of these limitations. As well as adapting to the physical limitation P2 changed her expectations of performance having decided that if the phone was not nearby she would not rush to answer, and the caller could phone again if needed.

Participants developed new ways of doing and modified responses to compensate for limitations in functioning, enabling continued participation in a range of usual life activates like driving, shopping and work:

> *I didn't drive at all. Well now I am because it's only from here up the street, down there and there I am. I don't even have to turn a corner and I drive real slow and my eyes are going, but I'm aware, as you said. I know my limitations and I'm aware. If I see a car coming I'll sit there and I'll wait and let it go. Before I'd just drive out, I had plenty of time but I don't take that risk anymore, I let them go. They're possibly wondering, why the hell's he sitting there waiting for me to go past? (laugh) No, I leave a big margin of error now, not a little one* (P1.2, 155).

Sometimes strategies developed in response to limitations, increased performance beyond previous functional capacity with productive results. For example, P5 became more organised and wrote notes to not forget important information, improving work performance which was noticed by his employer:

> *I'm a lot more organised than what I was before. He just goes* [swear word] *I can't believe how organised you are* (P5.2, 218).
>
> *..keep on top of it because I'm afraid that I might forget something. So while it's in my head, I'll do it, complete it and then put it to one side and put a sticky note on it. So then it's only a matter of scanning the paperwork and go oh yeah. Whereas before I'd store a lot of shit in my head and just worry about it later on, down the track. But I can't afford to do that because I'm too scared I'll forget something and it might be something major. It could come back and bite me on the butt, so I'm a*

> *lot more, how would you put it, pedantic about crossing my T's and dotting my I's now. In the paperwork side of thing and so I don't forget shit* (P5.2, 221).

Gaining help from others was another type of strategy that some participants had learned they needed. Help from family and friends became integrated into changed living situations and for some represented a reversal of roles and relationships where previously they had been the ones helping others. For the Indigenous participant this had special meaning where helping one another was expected, however the dynamic of a respected older female to provide care and support to children and grandchildren changed to rely on others to help her:

> *Yes. We help one and other. If not they do everything and I just lie down* (P7.2, 233). *If I'm not feeling good, they do it for me* (P7.2, 232).

Thinking about the future

Over time participants came to understand changes in their situation and developed strategies to continue their involvement in life activities. These experiences and thinking for some participants led to a consideration of future directions, incorporating notions of progression in functioning and the requirement for adaption to new circumstances.

Although participants didn't yet know the definitive outcomes of recovery they considered alternatives that ranged from plans for changes to the garden to bigger life decisions of moving from home. Thinking of the future seemed to reflect the combined variation of functional improvements and functional limitations experienced, as some thinking responded to restrictions and other thinking focused on ways to promote involvement in life. For example the same participant considered selling his house and business, but also thought about more immediate plans to improve his garden, valuing this as a productive activity and had other thoughts about different kinds of businesses he could run from home. Participants thought about options for supported accommodation and the need for public housing due to loss of income, but at the same time planned for positive life changes like purchasing a motorbike and options for volunteer work in place of paid work.

Experiences sometimes led to new directions in life where new purposes were discovered, for example P8 joined a disability advisory group and began thinking about becoming a counsellor, to provide peer support to other people with similar conditions as himself.

An exception to thinking of the future was also reported by one participant who preferred not to think beyond day to day concerns and this seemed to be a cultural way of thinking:

> *I'll wait until it happens. I just go from day to day. I try not to think about it. When I don't think about it I feel much better* (P7.2, 328).

Chapter Summary

The study found an overarching theme, *learning to live with an altered functional self*, which is described as a journey of learning and adaptation to unexpected changes to body structures and limitations in functioning. Processes of discovering, realising, planning for and taking action, gaining a deeper understanding of the changed functional self and determining adaptive, productive thinking and doing strategies are described in the three sub themes. The sub-themes were: r*ealising my functional self has changed, taking charge to restore my functional self* and *taking charge of my changed situation.* Participants actively engaged in a range of responses enabling continued participation in valued life activities. These responses incorporated the physical work of rehabilitation and importantly, the study findings revealed seemingly hidden, thinking and psychological and emotional responses.

These psychological aspects of the work of the person, were characterised in participants thinking about experiences of functional limitations, learning for themselves, problem solving, and the adaptive thinking and doing strategies devised. Additionally, expressed need and drive for independence, influenced responses to adversity, motivated, and were part of the psychological work participants engaged in.

The study also found the essential influence of context, through performance of everyday activities in home and community environments, was required for experiential learning throughout the journey. There were physical and psychological aspects to the influence of the contextual environment. Everyday activities, home and community environments provided physical form for demands of the task and of the environment, challenging participants to perform. Opportunities and challenges within activities and within the environment were needed for the thinking and psychological responses of assessment, judgement, planning and for determining actions. Anticipating the future, having hope and making tentative plans were part of the psychological and adaptive responses that were evident with passing time and were unfinished aspects to participants stories,

The purpose of this study was to find out about the experiences of discharge, transition and life after inpatient rehabilitation, shortly after leaving hospital and over the next few months. While discharge was an important event which precipitated responses described, the bigger story in the findings were the complex responses to changes in functioning, which began while in hospital, continued over time, and incorporated psychological and contextual components.

Chapter 4: Discussion

Introduction

The concluding chapter of this thesis discusses the study findings in relation to the existing literature. This qualitative study is distinctive in examining the person's experiences and perceptions following discharge from a mixed inpatient rehabilitation unit in the Australian setting. Furthermore, stories were collected shortly after leaving hospital and again over the next few months, while participants were experiencing and living with changes to their functioning as a result of an unexpected health event or newly acquired disability. The key finding of learning to live with an altered functional self was revealed as a journey of learning through experience, psychological adaptation and biographical transition that commenced while in hospital and continued after discharge. The demands of home and community life were central to realising the functional self had changed, taking action to restore functioning and, over time, taking charge of the changed situation.

These findings have implications for rehabilitation health professionals and service delivery. This chapter will consider these issues along with implications for future research and the limitations of this study.

Key Finding: Learning to live with an altered functional self

An important and valuable aspect of this study was the capturing of the person's perspective in descriptive detail. Unique insights into a complex and multifaceted journey of transition and adaptation were provided. Participants' stories described the physical, psychological and biographical work of rehabilitation and the role of context in these processes.

The process of psychological adaptation and biographical transition

Participants' stories began with experiences in hospital. Although they had suffered differing changes to their health, almost all participants verbalised their perception of the precipitating event, as a life threatening or near death experience. As recovery progressed, a realisation process commenced where the experience of changes to physical and cognitive functioning resulted in discovery, thinking, actions and a changed view of the functional self. With the passage of time and multiple experiences, an amalgamated view of the changed functional self was formed, incorporating improvements made, ongoing functional changes and adaptations/strategies employed to enable continued participation in valued activities.

Similar concepts of the psychological nature and work of rehabilitation are found in the literature. Kirkevold (2010) described three major themes occurring through rehabilitation and the months following hospitalisation for stroke survivors. These were: addressing bodily recovery and dealing with persistent bodily changes, re–establishing and restructuring of daily life, and biographical adjustment and transformation (Kirkevold, 2010, p. 37). A qualitative meta-synthesis of the experience of living with stroke by Salter, Hellings, Foley, and Teasell (2008) found an ongoing process of reinterpretation of the self and transformation, suggesting the stroke experience was a psychosocial transition. More recent research focusing on the first month home after stroke also described returning home as a psychosocial transition, involving activities of re-examining identity and reality of the new situation, reconnecting with previous important relationships and activities, and revisiting past lives (Pringle, Drummond & McLafferty, 2013, p 1991). The “Life Thread Model” of Ellis-Hill, Payne and Ward (2008) emphasises psychological aspects of “re-structuring world views and developing new ways of living” (p. 157). Rehabilitation as a personal journey where there is reconstruction and transformation of the self is also described by Pryor and Dean (2012).

Transition is emerging as a feature of the rehabilitation process. Cott et al. (2007) conceptualise rehabilitation as a “status passage” of transitioning from non-disabled to disabled person (p.1567). According to Hammell (2006), rehabilitation is a transitional stage and discharge is when the real journey begins because this is where biographical disruption as a result of impairment may require the person to undergo transition into a new way of being in the world (p.115). Turner, et al. (2007) describe transition as a distinct phase in the rehabilitation continuum and note it is often associated with increased stress, emotional distress and depression for individuals and family members.

In this study, learning to live with an altered functional self occurred over time as a series of thinking and doing responses to the different experiences of altered functioning. These responses contributed to experiential learning as the participant thought about situations that had occurred, while they were occurring and could anticipate future possibilities. Determining and learning different ways of doing were transition activities. Transition was experienced in different forms. The unexpected initial changes to health, and discharge from hospital were change events that triggered responses. Leaving hospital resulted in participants experiencing their altered functioning in a different environment, which challenged performance. This resulted in deeper understanding of limitations, but also provided opportunity for improvement and more varied activities. Adaptive responses to challenges encountered were facets of transition processes, as the person integrated changes, came to understand and take charge of their changed situation.

These multiple forms of transition exemplified in the findings of the current study align with Kralik, Visentin and van Loon (2006), who found that the word transition was used to describe a change event, but also involved the psychological processes of adapting to the change event or disruption. Acknowledgement of the change event was needed before engagement in the transition process could occur (Kralik et al., 2006). Hence, transition can be explained from the differing perspectives of: movement or passage between two points, a transitional process of transformation, integration and incorporation, and a process of inner reorientation as the person learns to adapt and incorporate new circumstances (Kralik et al., 2006, p. 324). Transition becomes a biographical transition when viewed from these perspectives.

Realising my functional self has changed

The findings of this study suggested that there was a difference between the theory of knowing and knowing through ‘discovering for myself’ that change to functioning had occurred. Discovering was described as happening by chance and the unexpectedness was impacted by the person’s assumptions and taking for granted of usual performance. Charmaz (2006) described a “jolt of awareness” when people take involvement or performance level in an activity for granted and discover differences between assumptions and actual actions (p. 31). By performing a familiar activity, measurement of performance can occur and obvious changes can be discerned (Charmaz, 2006, p. 31). Recent research confirms that experience with practical challenges and experience of essential aspects of physical possibilities and limitations was needed along with information in order to understand clinical conditions properly (Ringstad, 2013). These understandings enable autonomous choices and actions. Participants of this study needed to discover changes to enable understanding, planning and action.

Taking charge to restore my functional self

Participants' comparisons of their changed functioning with previous capabilities provided the motivation and direction for taking control to restore their functional selves. Levack, Kayes and Fadyl (2010), in a meta-synthesis of recovery and outcome from traumatic brain injury, describe both "effortful activity" to improve capacity and changing the way of thinking about oneself. The tension experienced between accepting the current situation and "striving for a better one" (p. 995) provided motivation and resulted in taking action. In the current study, re-awakening of the usual self and the desire to be in control and maintain independence were strongly expressed. Despite changes to functioning and the challenges of realising the serious nature of these changes, participants maintained the important self concept of independence. In addition, they experimented, pushed harder and learned new ways for doing. This result is consistent with research involving focus groups of people with a range of chronic conditions, which found that gaining control of the sense of self and holding on to one's identity was a theme that emerged spontaneously and strongly across different conditions and across time. "Self-knowledge of one's own disease and body was universally agreed to as being the most important prerequisite to gaining control" (Martin, Peterson, Robinson & Sturmberg, 2009, p. 10).

In the current study, the phenomenon of self talk was expressed in several participant stories. When recounting experiences some included the internal dialogue they had with themselves while engaged in a particular activity. While not examined in depth in this study, in the literature self talk is linked with improving self efficacy, as a form of cognitive behaviour therapy that is an untapped resource in rehabilitation (Robinson-Smith, Johnston & Allen, 2000). Self talk as a strategy for health empowerment can be used to promote positive thinking (Shearer, 2009). Charmaz (2006) suggests that constructing narratives helps in coming to terms with changes and perhaps self talk is a form of narrative helping the process of change. Self talk enabled an insight into the thinking processes of participants.

Participants in this study provided various examples of how they took control, expressed their desires, motivations and personalities. Participants incorporated understandings of changed functioning into their self concept as bodily functioning was not considered the same as the self. These conceptual distinctions of self from the functional self are supported by Charmaz (2006).

Taking charge of my changed situation

With time and opportunity for multiple experiences of performing everyday and life activities, participants gained understandings of an amalgamated different functional self. They took charge of their changed situation by determining adaptive strategies, making life decisions and planning for the future. Participants implemented strategies to enable performance of life activities that in this study were categorised into thinking and doing strategies. These findings are similar to a recent study of resilience and adjusting following stroke, where personal characteristics and employment of practical and mental strategies were key factors (Sarre, Redlich, Tinker, Sadler, Bhalla & McKevitt, 2013).

The determination of learning and adopting different ways of doing were important to enable continuation of valued activities. What was considered valued varied between participants, depending on specific likes and previous life patterns. According to Charmaz (2006), meanings of earlier activities depend on the place of the activity in the person's life and how closely it remains tied to the person's self concept. Being able to participate in a favourite activity nourishes and validates self.

The journey of learning to live with an altered functional self was continuing and while the future was still not known by the participants of this study, they maintained hope with tentative planning for the future. Kirkevold (2010) proposed that major recovery and adjustment occur mostly after discharge within the life context of the person, and this phase is necessary before it is possible to get on with life and re-establish a life perceived as "worth living" (Kirkevold, 2010, p. 37).

The findings of psychological adaptation and transition occurring from hospital to home and community also highlighted the amount of work that participants engaged in. There seemed to be a disparity between the provision of physical based rehabilitation and recognition within the inpatient setting of need for this other work, and a consequent lack of provision of psychological support.

The role of context in rehabilitation

In this study, the importance of the environmental context for performance and experiential learning was evident in the need for participants to experience limitations in functioning, while performing every day activities and in differing environments. The specific contextual parameters included: the person and their aspirations, personality and characteristics; the type of activity and inherent performance demands; and the location with its various structural features which acted as facilitators or barriers to performance.

Participants of this study were not able to fully realise the impact of their functional changes until they experienced them out of the hospital environment. While challenging and sometimes difficult, these experiences also enabled problem solving, learning new ways and real opportunities to improve functioning.

This indicated that environment has the potential to be a rehabilitative intervention if understood and designed to maximise the therapeutic context. Sanford (2012) describes human function in terms of human abilities, such as learning, ambulating, seeing, communicating, and hearing. Functionality, however, is a product of the interaction between demands exerted by physical form of the environment, human function and demands of the activity. The influence of the environment upon functionality, as described by Sanford (2012), was evident in these findings and the dynamic relationship between the person and the environment proved crucial to learning and adaptive processes.

Participants were strongly focussed on leaving hospital and appeared to equate their physical performance with ability to go home. The focus upon impairments, therapy and exercise when in hospital was important for individual improvements. However, the meaning of everyday activities and environment out of hospital seemed to align with the person’s concept of independence and return to living their usual lives. A variety of activities across environments that were not always about formal therapy were also of therapeutic benefit.

Consideration of environmental design and form, performance of everyday activities, and broadening therapeutic input, raises questions about the meaning and focus of rehabilitation. Research by Cott (2004) identified important components for person-centred rehabilitation service delivery. These were: individualisation of programs, mutual participation with decision making and goal setting, outcomes that are meaningful, provision of appropriate and timely information and education, emotional support from family and peer involvement and coordination and continuity. “Preparation for life in the real world” was considered the key to successful person-centred rehabilitation (Cott, 2004, p. 1419). The person’s uniqueness and their subjective experience, personal history and emotions should all be taken into account (Leplege et al., 2007).The context of the rehabilitation process should include the person’s unique environment and acknowledge interdependence with others who are important in their lives (Leplege et al., 2007). The principles of activity, participation and dynamic interaction with the person and environmental context, fits with the language of the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation, 2002). The findings of this study support relevance of ICF to rehabilitation.

The importance of the ‘person in context’ has been highlighted by Pryor and Dean (2012) and findings of the present study underline the need for real life learning opportunities which involves seeing and experiencing the self in real life situations. Where rehabilitation is viewed as being about living and not about treating or curing, the importance of the ‘lived body’ is incorporated (not just the physical body), and includes “the body as it is experienced and as it interacts with the self and the world” (Hammell, 2006; p, 107). Therefore, rehabilitation interventions need to be tailored to lives not just to bodies (Hammell, 2006).

The place and role of the rehabilitation professional, in particular the rehabilitation nurse, needs to be considered in light of the findings around context. While interactions with health professionals were not a specific focus of this study, some impressions were gained. Participants gave examples of positive responses to information received from health professionals which began the learning process. Some interactions were supportive and encouraging of efforts by participants, but others were perceived negatively and disempowering. The amount of work participants engaged in seemed largely invisible to the health professionals surrounding the person. Therefore, there appeared to be a lack of acknowledgment and understanding of the psychological and biographical transition. Theories of health empowerment provide a guide to possibilities and potential direction. Health empowerment, an “intervention designed to promote the use of personal resources and social-contextual resources with the goal of enhancing well-being” (Shearer, 2009, p. 4), is congruent with the findings in this study.

Nurses practicing from a health empowerment perspective incorporate strategies that foster awareness of, and access to, personal and social-contextual resources, and assists the person to purposefully work towards attainment of their goals (Shearer, 2009). Recognition of the need to prepare health professionals to properly support and assist self-management following stroke has resulted in the development of the Bridges Stroke Self-Management Program (St George’s University, 2013). This program provides workshops for the health professional, enabling changes in practice from the role as 'experts' to a more collaborative therapeutic relationship to support self-management (Jones, Livingstone & Hawkes, 2013). Additionally, it provides resources for the stroke survivor to support the work of recovery.

Finding ways to maximise the therapeutic benefit of the environment, broadening therapy to include a range of activities, with a focus upon the 'lived body', learning about and employing health empowering, collaborative strategies for self management would advance the relevance of rehabilitative practice and support the findings of this study.

Implications of the study findings

A number of implications arise from the findings of this study. These relate to rehabilitation service delivery, the preparation of health professionals for their role in rehabilitation and future research.

Implications for rehabilitation service delivery

The findings of this study highlight that while discharge is an important milestone and catalyst within the continuum of learning and adaptation that begins in hospital, it was not the main focus of participants' stories. Instead, discharge from inpatient rehabilitation was just one aspect of the journey of learning to live with an altered functional self. The unexpected information and detailed descriptions provided by participants about their experiences while in hospital and after leaving hospital have broader implications for rehabilitation service delivery.

These implications arise from the process of psychological adaptation and biographical transition and the role of context in rehabilitation. More specifically they relate to the work of rehabilitation, the need for appropriate support during hospitalisation and beyond, locations for rehabilitation service delivery and the focus of rehabilitation.

The psychological and biographical work of rehabilitation and support needs of the person

The study suggested the rehabilitation ‘work’ of the person included significant psychological components. A range of thinking and psychological responses were described; as the person was discovering, realising impairments, while thinking, planning, determining actions and adaptive strategies. The strong desire to have control and strive for independence and the preservation of the sense of self and self concept, despite difficult experiences and challenges to the functional self while re-establishing life activities and roles, emerged within all participants’ stories. This ‘work’ of the person has implications for provision of support along the whole continuum of rehabilitation service delivery.

The psychological and biographical transition processes experienced, seemingly remained hidden and internalised, and this work was performed with no support from qualified psychological health professionals for all participants except one, where private sessions from a psychologist were contracted for a limited time frame while an inpatient. There was no such support provided after discharge. Furthermore, there was little evidence of rehabilitation health professionals fully understanding the nature of participant’s experiences. The findings support incorporation of formal and informal psychological support at all stages, while an inpatient and after discharge, as necessary to support the work of the person learning to live with altered functioning. As well as affirming the importance of clinical psychology expertise within the rehabilitation service, the findings have implications for how health professionals perceive and interact with the person and address psychosocial needs.

The importance of allowing and supporting control by the person and recognising individual ways for expressing this need for control and drive for independence is also highlighted in this study. Systems, procedures and attitudes need to foster and protect, not inhibit, the reawakening of the independent self. Study participants recounted many examples of their interactions with health professionals, and although the content was not always relevant to the study focus, the importance of interaction, communication and relationship development was undeniable. The benefits of and requirement for developing therapeutic relationships and partnership with the person, and person centred care is well recognised in the rehabilitation arena and this study emphasises the essential nature of this from the person's perspective. However, health professionals need to understand the psychological imperatives of the person and possess a measure of self confidence and interpersonal skills in communication and negotiation for partnership and attainment of the person's aspirations.

While relevant for all who are engaging with the person, nursing as the only discipline with a 24 hours presence in the inpatient setting has a vital role to play in assisting the person with coping and stress tolerance by providing caring and compassionate psychological support. All nurses need the skills to incorporate health empowering strategies (Shearer, 2009) and support self-management (Jones, 2013). Enabling skill development, and allowing time for these more 'invisible' aspects of caring has implications for how nursing work is perceived, measured, funded and supported by health systems. There is potential for a greater realisation, utilisation and recognition of an enhanced role of the nurse in rehabilitation to support the psychological and biographical work undertaken by patients both in the inpatient setting and extending out of the hospital.

Influence of context and ‘work’ of the person on rehabilitation service design and operations

The essential influence of the environmental context, enabling performance of everyday activities has implications for physical design, and the focus and location of rehabilitation service provision. It was important for participants to experience self discovery of limitations in functioning for meaning, understanding and action to occur. The performing of everyday activities in the inpatient and home environment enabled this realisation process. The contextual environments of home and community were particularly identified as crucial by providing opportunity for multiple experiences. This leads to thinking about where, when and how rehabilitation services can be provided.

The importance of the experiential learning context in the study findings, suggests the need for the built environment to be designed to minimise the medical/institutional aspects of the hospital environment, to provide space for required daily life activities and allow naturally occurring opportunities for functional performance. Environmental design as a rehabilitation intervention makes therapeutic use of ‘functionality’ (the product of interaction between demands exerted by physical form and human function) and of ‘occupational performance’ (the outcome of transactions among person, occupation, and environment) (Sanford, 2012). These environmental design principles are applicable in the inpatient, home and community environments, and can be maximised for beneficial outcomes for the person. The findings suggest that a home or homelike environment contains the form, functionality and occupational performance features to create the necessary demand to be considered therapeutic rehabilitation intervention (Sanford, 2012).

A range of inpatient rehabilitation and community environments incorporating design features to maximise experiential learning through performance of everyday activities and participation is supported by this study. Ideas for expanded rehabilitation service provision in differing environments are described and supported in rehabilitation strategy development and service redesign documents in Australia and internationally. A continuum of service includes provision of rehabilitation in the acute sector, dedicated rehabilitation inpatient units, community based and ambulatory care, continuing care and outreach services (Australian Rehabilitation Alliance (ARA), 2011; National Rehabilitation Hospital, 2009; *NSW Health, 2011; Scottish Executive, 2007*).

The expressed strong desire to get out of hospital, and the influence of context of home and community, in the study findings, support consideration of earlier discharge in combination with community based support. Other service options include; more home like temporary or transitional accommodation with support, for those whose usual home is located long distances away, or for use as carer training environments, provision of rehabilitation in the home and other ambulatory care service models. There is potential for improved outcomes, greater satisfaction and cost benefits, if ‘in-home’ rehabilitation services are combined with shortened length of inpatient stay (Anderson, Ni Mhurchu, Brown & Carter, 2002; Mak, Cameron & March, 2010; National Ageing Research Institute, 2004). However, the nature of rehabilitation service provision ‘in-home’ would need to foster and support self determination and adaptive endeavours of the person, and not just be a transplant of therapy/treatment modalities from the inpatient setting. A key component is the attitude and approach of the health professional being responsive to different dynamics in the home environment (von Koch, Wottrich & Holmqvist, 1998), and being aware of the need to retain the integrity and meaning of home (Tamm, 1999). As well as the potential therapeutic benefit, the shortening of length of stay with provision of community based rehabilitation services and alternative accommodation options, could be more cost effective and address issues to do with bed management and measures of health service efficiency (Anderson et al., 2002; Doig & Amsters, 2006).

Purpose built infrastructure, with management, staffing and operational systems planned to promote environmental design concepts and support distinctive rehabilitation care would need to be separated from the influences and competing demands of the acute hospital/medical model and systems. Otherwise different priorities could impact upon the quality aspects of complex rehabilitation and discharge needs. The standards for operation of rehabilitation units as published by the Australasian Faculty of Rehabilitation Medicine (AFRM) provide guidelines describing and supporting aspects of service specialisation (AFRM, 2011). Improving functionality of rehabilitation services also has the potential to impact positively upon the whole health system; by improving patient flow and outcomes in acute care if engaged early and through increased access to rehabilitation beds/services by developing models of rehabilitation that provide alternatives to inpatient care (New & Poulos, 2008).

When considering the location and accessibility of rehabilitation services in the NT, cultural implications arise, particularly with an Indigenous population of 30% of the total NT population. Provision of rehabilitation services requires different contextual environments to that available in standard hospital and health services. Indigenous users of the rehabilitation inpatient service who came from remote locations, were not included in this study, but form a large percentage of inpatients of the service setting of this study. The demographic picture obtained from the RDH rehabilitation retrospective discharge audit in 2008, found that 40% of inpatients were discharged to rural and remote locations (Widdall, 2008).

Implications arise around provision of rehabilitation in the cultural, personal and community context. These issues are further complicated by the lack of availability of rehabilitative service provision in smaller regional hospitals and at the level of local community, where disability support services are extremely limited or non-existent. This means that many Indigenous rehabilitation inpatients are isolated and separated from home and country by long distances, often for lengthy time periods, with the rehabilitation episode of care at the very end. Consequently, the Indigenous person from rural or remote regions spends a longer time in the hospital rehabilitation inpatient environment or there is precipitous discharge due to homesickness and cultural isolation (Faux, Ahmat, Bailey, Kesper, Crotty, Pollack & Olver, 2009). Changes to service design and operations from a cultural perspective with the added demands of distance would need careful consideration, but are warranted for equity, access and relevance.

Influence of context and ‘work’ of the person on the focus for rehabilitation

In addition, to influences upon physical design and organisational system aspects of rehabilitation service delivery, the role of context and ‘work’ of rehabilitation has implications for the nature and focus of rehabilitation as a therapeutic intervention.

In this study, participants took action to restore functional limitations requiring the performance context of everyday activities for comparisons of functioning with previous capacity, and over time learned different ways to continue participating in valued life roles and activities. Implications about the definition and focus of therapy and treatment interventions arise when considering these contextual aspects for performance.

Currently rehabilitation standards quantify the amount of therapy required daily and weekly (ranging from 15 hours a week to 3 hours a day) to be necessary within an inpatient rehabilitation service. Therapy time is measured as time with allied health professionals. Additionally, proposals for delivering weekend therapy and increasing intensity of therapy are recommended (AFRAM, 2011; ARA, 2011; NSW Health, 2011). The findings of this study suggest a broader definition and understanding of what constitutes therapy and has implications for who delivers therapeutic input.

Rehabilitation grounded in the person's context, including a range of activities in an environment enabling these activities to occur as naturally as possible, broadens understandings about what is considered therapeutic input. For example, the role and place of recreational, leisure and social activities become more valued and recognised as therapeutic opportunities, just as important as 'treatment' orientated therapy. Narrow understandings of rehabilitation therapy being confined to allied health professional intervention, with the role of therapy assistants and nursing to be limited to continue and reinforce therapy treatment, ignores the greater capacity of the rehabilitative environment within which the person is functioning, and the inner resources of the person. Narrow interpretations of rehabilitative care, can diminish the role of nursing and other non allied health personnel. The findings of this study support the resilience and resourcefulness of participants who cared about overcoming physical and cognitive limitations but were also endeavouring to resume valued life activities.

The broader understanding of therapeutic intervention suggested by this study, opens up support to come from nursing who have the professional underpinning to view the person from holistic and functional perspectives. The value of nursing involvement in rehabilitation home services has precedence (NARI, 2004, p. 15; NSW Department of Health, 2006). Community based nursing consultation roles are well established in areas of chronic disease, complex care needs, rehabilitation, and in developing new and emerging nurse led models of community and primary care (Chiarella, 2008).

Implications for educational preparation of health professionals

The implications arising from the process of psychological adaptation and biographical transition and from the role of context in rehabilitation, suggest changes are needed in the educational preparation of health professionals. For example;

1. Inclusion of a multidisciplinary component for all undergraduate professional disciplines to encourage early understanding of differing roles.
2. Incorporating principles of ICF, for understanding the focus of rehabilitation at the level of activity and participation in life, and the importance of environmental and personal factors.
3. Preparation to practice in a person centred environment and for changing from the role of ‘expert’ to ‘collaborator’ enabling and supporting self-management.

Education to include chronic disease and disability models of care for supporting self management and differing models for engaging and encouraging health literacy across differing cultures.

Preparation for the health professional to work in teams, communication skills for negotiation in a team environment and skills for supporting the person in emotional, psychological and emotional pain.

Implications for future research

The findings of this study suggest further research is required. In particular, research of the experiences and perceptions of discharge and return to community life of the Indigenous inpatients including those who live in remote locations outside the Darwin region. The personal, family and community impact of longer separation from home due to lack of service in the rural and remote areas of the NT is well known. Culturally appropriate research into this area would provide valuable insights into the cultural context and needs for support closer to community and country of a significant proportion of users of the rehabilitation service. This research would provide insights for achieving culturally competent and safe health design that could have relevance beyond the NT.

Research into community based and ambulatory care models enabling earlier discharge from the rehabilitation inpatient unit and piloting a nurse led ‘in-home’ rehabilitation model of care is suggested. Australian and international research has tended to focus on multidisciplinary models structured to operate in more traditional therapy/treatment orientated ways. Nursing models for community rehabilitation in chronic disease and other specialities like palliative care, could be used as a guide. Developing a flexible service model that could provide mobile support to home for trial leave and early discharge and into temporary or transitional living environments, could be cost effective and increase access to the benefits of rehabilitative care in the acute sector by shortening length of stay.

The participants of this study had unfinished stories. Research over extended periods of time would provide more insights into long term outcomes, needs and perceptions.

Limitations of the study

Limitations of the study are acknowledged. Although rich and extensive data were provided, the number of participants was relatively small at eight and experiences over a longer time frame (over 12 months) were not captured. The amount of data obtained necessitated some limitations and narrowing of analysis for the purposes of this thesis. The experiences and perceptions of family members of persons recently discharged from inpatient rehabilitation would have been valuable.

Only one Indigenous participant from the Darwin region was recruited in the time available, and this limited analysis and comparison for differences between non-Indigenous and Indigenous experiences and perceptions. Furthermore, Indigenous people from remote locations were not included. A different design and methodology would be required to include these rehabilitation service users.

The study focus was on persons with a range of health conditions that required rehabilitation in a mixed rehabilitation service. Although the nature of many experiences described had commonality, there may be distinctions between diagnostic groups that could be ascertained when focusing specifically on a larger number from each diagnostic group. For example, there could be differences in experiences and specific concerns following discharge after lower limb amputation, spinal cord injury, stroke and brain injury.

Conclusion

This qualitative study has examined the person’s experiences and perceptions following discharge from a mixed inpatient rehabilitation unit in the Australian setting. Stories were collected while participants were experiencing and living with changes to their functioning, as a result of an unexpected health event or newly acquired disability. These important attributes contribute to the meaning and significance of the findings.

The key finding of learning to live with an altered functional self was revealed as a journey of learning through experience, psychological adaptation and biographical transition that commenced while in hospital and continued after discharge. Additionally, the importance of context was highlighted and was essential to the physical and psychological work of the person.

Implications of the findings require: changes in understanding and supporting the person undergoing biographical transition, changes in environmental design and location for rehabilitation, and broadening notions of therapy and roles for nursing, Furthermore, consideration of alternative community supported and ambulatory models of care to enable earlier discharge, using the environment as a therapeutic intervention, is potentially beneficial for the person. Improving the functionality of the health system through increased access to rehabilitation would have broader system benefits. The study findings provide direction for both service development and rehabilitation practice improvements, as well as direction for future research.

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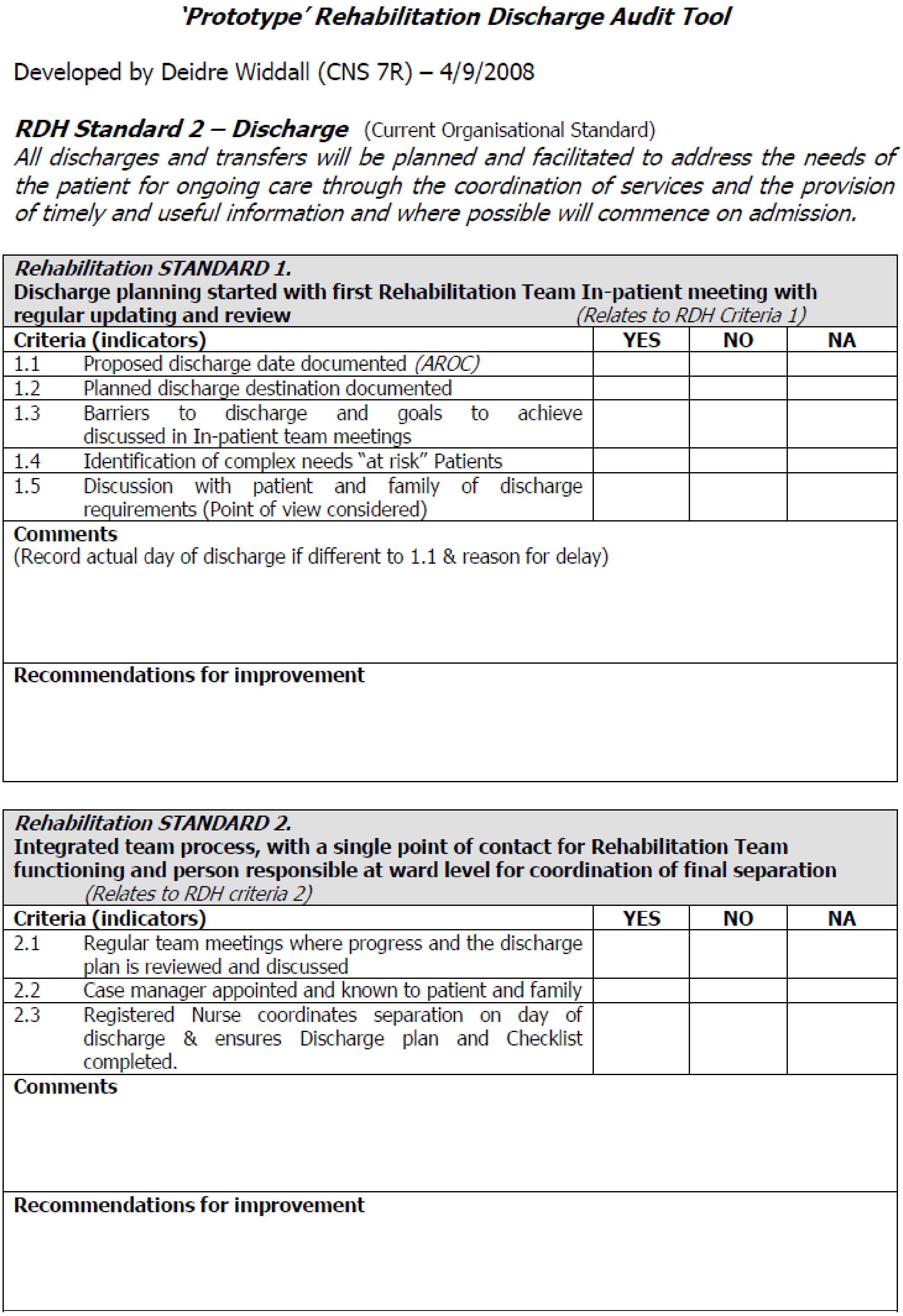
Appendix A: Rehabilitation Discharge Audit Tool



'Prototype' Rehabilitation Discharge Audit Tool

Developed by Deidre Widdall (CNS 7R) – 4/9/2008

RDH Standard 2 – Discharge (Current Organisational Standard)
All discharges and transfers will be planned and facilitated to address the needs of the patient for ongoing care through the coordination of services and the provision of timely and useful information and where possible will commence on admission.

Rehabilitation STANDARD 1.
Discharge planning started with first Rehabilitation Team In-patient meeting with regular updating and review *(Relates to RDH Criteria 1)*

Criteria (indicators)	**YES**	**NO**	**NA**
1.1 Proposed discharge date documented *(AROC)*			
1.2 Planned discharge destination documented			
1.3 Barriers to discharge and goals to achieve discussed in In-patient team meetings			
1.4 Identification of complex needs "at risk" Patients			
1.5 Discussion with patient and family of discharge requirements (Point of view considered)			

Comments
(Record actual day of discharge if different to 1.1 & reason for delay)

Recommendations for improvement

Rehabilitation STANDARD 2.
Integrated team process, with a single point of contact for Rehabilitation Team functioning and person responsible at ward level for coordination of final separation
(Relates to RDH criteria 2)

Criteria (indicators)	**YES**	**NO**	**NA**
2.1 Regular team meetings where progress and the discharge plan is reviewed and discussed			
2.2 Case manager appointed and known to patient and family			
2.3 Registered Nurse coordinates separation on day of discharge & ensures Discharge plan and Checklist completed.			

Comments

Recommendations for improvement

Rehabilitation STANDARD 3.
Comprehensive assessment of discharge needs

Criteria (indicators)		**YES**	**NO**	**NA**
3.1	Discussion with patient, family, carers or Community of specific discharge requirements			
3.2	Home location & environment assessed by home visit by OT and/or PT or remote agency assessment if outside Darwin region. (Safety, mobility, modifications, supports available if needed)			
3.3	Need for equipment post discharge assessed and TIMES registered if eligible. (Mobility, ADL aids, Personal alarm, other)			
3.4	Assessment of ongoing support needs. (Personal care, health monitoring, transport assistance, other community support services)			
3.5	Assessment of education and training needs pre discharge of patient, family, carers, and community agencies. (Health condition, medication administration, specific care needs, use of equipment)			
3.6	Assessment of travel requirements. "Travel Risk AX" to be completed if patient to travel outside Darwin Region or is travelling alone			
Comments				
Recommendations for improvement				

Rehabilitation STANDARD 4.
Ongoing integrated Rehabilitation Team discharge planning *(Relates to RDH criteria 3)*

Criteria (indicators)		**YES**	**NO**	**NA**
4.1	Regular team meetings to review progress and results of assessments for discharge			
4.2	Documentation of a Discharge Plan based on assessments and consultation with patient, family, relevant others			
4.3	Discharge Checklist commenced with identified needs listed			
4.4	Referral to community support services, ACAT, Transitional Community service, Local Area Coordinator, Patients GP, or Community Health Clinic, any other.			
4.5	Ordering of equipment and items identified in assessment phase			
4.6	Commencement of education and training as identified in assessment phase			
Comments				
Recommendations for improvement				

Rehabilitation STANDARD 5. **Effective communication and information sharing between Rehabilitation Team and patient, family, community stakeholders** *(Relates to Criteria 4 & 7)*				
Criteria (indicators)		**YES**	**NO**	**NA**
5.1	Team meeting held with patient and family to review progress, proposed discharge plan and proposed discharge date			
5.2	Additional Team meeting with patient, family **and** community stakeholders where "at risk" or complex discharge			
5.3	Record of meeting documented in patient notes and copy sent to all present			
5.4	Contact made with LMO prior to discharge			
5.5	Consent for provision of information to other agencies			
5.6	Documented communication with remote therapists and service providers prior to discharge			
5.7	Confirmation of referrals made and provision of services as per discharge plan			
5.8	Rehabilitation Patient Discharge Summary completed and dispatched on day of discharge (Addressees: LMO, any community service provider involved) *(ACHS Indicator 4)*			
5.9	Discharge travel arrangements and Itinerary confirmed verbally and faxed to community agencies taking on responsibility for health care of discharged patient (if out of Darwin Region)			
Comments				
Recommendations for improvement				

Rehabilitation STANDARD 6. **Ongoing Health Management Plan developed and agreed prior to discharge** *(Relates to RDH criteria 3 &7)*				
Criteria (indicators)		**YES**	**NO**	**NA**
6.1	Discharge Plan includes relevant Health Management issues identified and discussed during meetings			
6.2	Medication administration competency determined prior to discharge (If not - an alternative plan is in place)			
6.3	Plan includes means for ongoing provision of medications and medical review			
6.4	Where specific health needs, documentation of ongoing health monitoring and support arrangements. (eg Continence, Spinal Cord Injury, Diabetes, Wound care)			
6.5	Education and training in these areas provided to patient, family, carer prior to discharge			
6.6	Information provided on how to contact those providing ongoing health monitoring and support in the community			
6.7	Referral to Lifestyle support agencies (Alcohol and Drug, Quit, Community Mental Health)			
Comments				
Recommendations for improvement				

Rehabilitation STANDARD 7.
All aspects of the Rehabilitation Discharge Plan is implemented prior to discharge
(Relates to RDH criteria 5 & 6)

Criteria (indicators)	YES	NO	NA
7.1 Home modifications completed			
7.2 Equipment and resources identified obtained prior to discharge			
7.3 Discharge Checklist utilised and completed			
7.4 Education and training required for patient, family, carer or other is completed			
7.5 Key stakeholders in community informed of discharge date and any support services ready			
7.6 Patient and family informed and agree with discharge date			
7.7 Transport arrangements made			
Comments			
Recommendations for improvement			

Rehabilitation STANDARD 8.
Readiness for discharge is assessed and evaluated ensuring safety and quality of discharge

Criteria (indicators)	YES	NO	NA
8.1 Home Visit prior to discharge with patient, family, carer (Safe environment, equipment has been delivered, Utilities functioning, food in house, money for immediate needs etc)			
8.2 Trial day leave (where appropriate)			
8.3 Graduated Discharge and overnight leave			
8.4 Outcome of Leave discussed with patient, family, carer, community stakeholders			
8.5 Adjustments to Discharge Plan made if needed			
8.6 All test results are known prior to discharge and health is assessed as stable for discharge by medical and nursing			
8.7 Team and Medical agreement that patient is ready and safe for discharge documented by Case Manager or delegated team member if unavailable			
8.8 Registered Nurse responsible at time of separation completes RDH Discharge document and Rehabilitation Discharge checklist, confirms 'Travel Risk Ax' (where relevant) matches travel arrangements and documents separation details in patient notes.			
8.9 Separation/Discharge aborted where deemed incomplete or unsafe			
Comments			
Recommendations for improvement			

Rehabilitation STANDARD 9. **Continuity of care and follow up arrangements made**			
Criteria (indicators)	**YES**	**NO**	**NA**
9.1 Discharge Plan is reviewed after discharge (Patient, family, carer and community stakeholders)			
9.2 Confirmation of safe arrival of patients travelling outside of Darwin Region			
9.3 Appointments for outpatients and Rehabilitation Consultant made			
Comments			
Recommendations for improvement			

Notes on Prototype Rehabilitation Discharge Audit Tool

The Standards and Criteria listed are not necessarily activities performed in sequential manner, as some aspects of the rehabilitation discharge process are cyclical.

Definition of "at Risk" or complex patient or potentially problematic Discharge

- Living alone
- Home is in a rural or remote location
- Homeless or accommodation has become inappropriate for functional status
- Being frail or aged
- Having multiple and or poorly managed health problems
- Having multiple health problems and not having prior community health and support services in place
- Not having a regular LMO
- Health care shared by a number of medical practitioners
- The presence of an ill, frail or incapable carer
- When patients are unwilling to participate in making discharge plans
- Being unrealistic about ability to manage in the community post discharge
- Family conflict about the patient's ongoing independent community living arrangements
- When patients are taking multiple medications and there are problems with compliance (including impaired cognition or dexterity difficulties)

Definition of community stakeholders

Community Health Centres (Local and rural and remote)
Dept. of Disability And Aged – Rural and Remote trans-disciplinary therapists
Specialist Adult Services
General Practitioners
Community Health Nurses and Aboriginal Health Workers
Specialist Community Nurses, Spinal, Continence, Wound, Respiratory
ACAT
Home care support services
Public Housing
Public Guardian
Neighbours, friends, Family, extended family
Any Other….

Appendix:B Ethics Forms

Dear Deidre

Application Number: 175/09

Title: An exploration of individuals' and their families' experiences and perceptions of transition from inpatient rehabilitation to the community.

The Issue: The Flinders Clinical Research Ethics Committee (FCREC) has reviewed and approved the above application under the expedited review program. Your project may now commence.

Approval Period: 4 June 2009 to 4 June 2012

Please retain a copy of this approval for your records. You are reminded of the conditions of continued ethical approval below.

TERMS AND CONDITIONS OF ETHICAL APPROVAL

Final ethical approval is granted subject to the researcher agreeing to meet the following terms and conditions:

1. Compliance with the *National Statement on Ethical Conduct in Human Research* (2007) & the *Australian Code for the Responsible Conduct of Research* (2007)

2. To immediately report to FCREC anything that may change the ethical or scientific integrity of the project.

3. To regularly review the FCREC website and comply with all submission requirements as they change from time to time.

4. Submit an annual report on each anniversary of the date of final approval and in the correct template from the FCREC website

5. Confidentiality of research participants MUST be maintained at all times.

6. A copy of the signed consent form must be given to the participant unless the project is an audit

7. Any reports or publications derived from the research should be submitted to the Committee at the completion of the project.

8. Report Significant Adverse events (SAE's) as per SAE requirements available at our website.

Kind Regards

Tamara Rusby
Executive Officer for the
Flinders Clinical Research Ethics Committee
and Clinical Drug Trials Committee

Human Research and Ethics Department
Southern Adelaide Health Service
Room 2A 221
Flinders Medical Centre Bedford Park SA 5042
T: 08 8204 4507 or Fax: 8204 4586
Email: tamara.rusby@health.sa.gov.au
Website: http://www.flinders.sa.gov.au/research/pages/ethics

menzies
school of health research

PO Box 41096, Casuarina NT 0811, Australia
John Mathews Building (Bldg 58),
Royal Darwin Hospital Campus, Rocklands Dve, Casuarina NT 0810
Ph: 08 8922 8196 | Fax: 08 8927 5187 | Web: www.menzies.edu.au
ABN: 70 413 542 847

discovery for a healthy tomorrow

Reference No: 09/48
Please quote this number in all correspondence

21st December, 2009

Ms Deidre Widdall
PO Box 41827
CASUARINA NT 0811

Dear Ms Widdall,

Re: 09/48 An exploration of individuals' and their families' experiences and perceptions of transition from inpatient rehabilitation to the community

The Human Research Ethics Committee of the NT Department of Health and Families and Menzies School of Health Research thanks you for taking the time to rework your application and submit for expedited review by the Fast Track Committee. The Committee has considered and approved your application.

Full approval is now granted. The Committee is satisfied that the research proposal meets the requirements of the NH&MRC National Statement on Ethical Conduct in Human Research, 2nd ed, 2007.

This approval will be ratified at the next meeting of the Human Research Ethics Committee to be held 17/2/2010. Please note that HREC approval applies only to research conducted after the date of this letter.

Approved Project timeline: 1/12/2009 to 30/8/2011.

This approval is for a period of twelve (12) months. A project progress report is required on or before **1/12/2010**

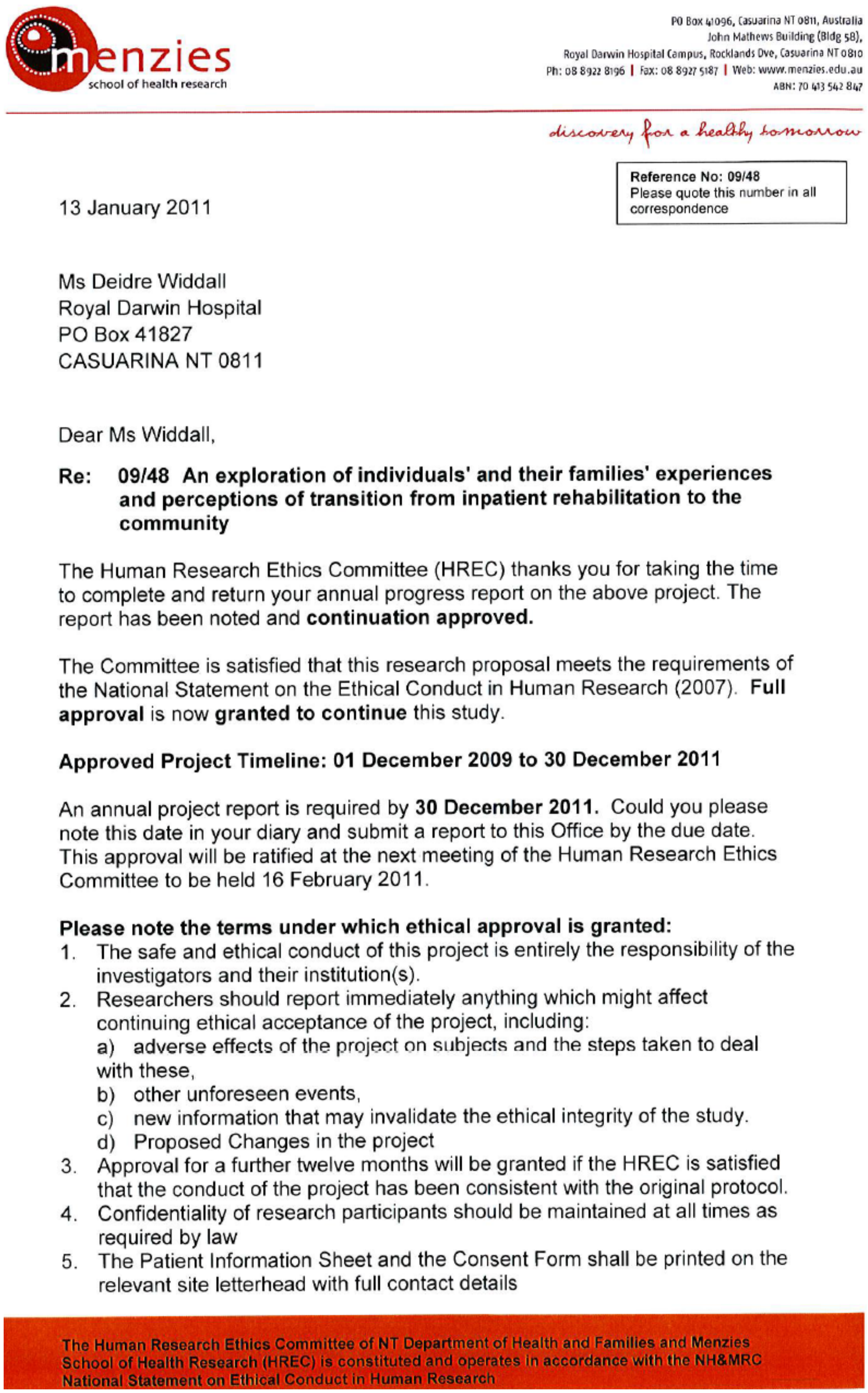
Please note the terms under which ethical approval is granted:

1. The safe and ethical conduct of this project is entirely the responsibility of the investigators and their institution(s).
2. Researchers should report immediately anything which might affect continuing ethical acceptance of the project, including:
    a) adverse effects of the project on subjects and the steps taken to deal with these,
    b) other unforeseen events,
    c) new information that may invalidate the ethical integrity of the study.
    d) Proposed Changes in the project
3. Approval for a further twelve months will be granted if the HREC is satisfied that the conduct of the project has been consistent with the original protocol.
4. Confidentiality of research participants should be maintained at all times as required by law
5. The Patient Information Sheet and the Consent Form shall be printed on the relevant site letterhead with full contact details
6. The Patient Information Sheet must provide a brief outline of the research activity including, risks and benefits, withdrawal options, contact details of the researchers and must also state that the Human Research Ethics Secretary can be contacted (telephone and email) for information concerning policies, rights of participants, concerns or complaints regarding the ethical conduct of the study.

7. The Committee must also be notified at the completion of the project.

Yours sincerely

Dr Michael Nixon
Chair
Human Research Ethics Committee
of NT Dept of Health & Families
and Menzies School of Health Research



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ABN: 70 413 542 847

discovery for a healthy tomorrow

Reference No: 09/48
Please quote this number in all correspondence

13 January 2011

Ms Deidre Widdall
Royal Darwin Hospital
PO Box 41827
CASUARINA NT 0811

Dear Ms Widdall,

Re: 09/48 An exploration of individuals' and their families' experiences and perceptions of transition from inpatient rehabilitation to the community

The Human Research Ethics Committee (HREC) thanks you for taking the time to complete and return your annual progress report on the above project. The report has been noted and **continuation approved.**

The Committee is satisfied that this research proposal meets the requirements of the National Statement on the Ethical Conduct in Human Research (2007). **Full approval** is now **granted to continue** this study.

Approved Project Timeline: 01 December 2009 to 30 December 2011

An annual project report is required by **30 December 2011.** Could you please note this date in your diary and submit a report to this Office by the due date. This approval will be ratified at the next meeting of the Human Research Ethics Committee to be held 16 February 2011.

Please note the terms under which ethical approval is granted:

1. The safe and ethical conduct of this project is entirely the responsibility of the investigators and their institution(s).
2. Researchers should report immediately anything which might affect continuing ethical acceptance of the project, including:
   a) adverse effects of the project on subjects and the steps taken to deal with these,
   b) other unforeseen events,
   c) new information that may invalidate the ethical integrity of the study.
   d) Proposed Changes in the project
3. Approval for a further twelve months will be granted if the HREC is satisfied that the conduct of the project has been consistent with the original protocol.
4. Confidentiality of research participants should be maintained at all times as required by law
5. The Patient Information Sheet and the Consent Form shall be printed on the relevant site letterhead with full contact details

The Human Research Ethics Committee of NT Department of Health and Families and Menzies School of Health Research (HREC) is constituted and operates in accordance with the NH&MRC National Statement on Ethical Conduct in Human Research

6. The Patient Information Sheet must provide a brief outline of the research activity including, risks and benefits, withdrawal options, contact details of the researchers and must also state that the Human Research Ethics Secretary can be contacted (telephone and email) for information concerning policies, rights of participants, concerns or complaints regarding the ethical conduct of the study.
7. The Committee must also be notified at the completion of the project.

Yours sincerely

Dr Gurmeet Singh
Deputy Chair
Human Research Ethics Committee
of NT Dept of Health
and Menzies School of Health Research

Larrakia Nation
Aboriginal Corporation
PO Box 42043
CASUARINA NT 0811
Email Address:Catherine.holmes@larrakia.com
Phone: (08) 89 483733
Fax: (08) 89 483488

Deidre Widdall
c/- Menzies HREC
RDH Campus
Darwin

13 October, 2009

Dear Ms. Widdall,

Please accept this letter as formal notification of the Larrakia Nation Board of Director's decision relating to your research proposal entitled, *An exploration of individuals' and their families' experiences and perceptions of transition from inpatient rehabilitation to the community*.

The Board have raised no concerns or objections relating to your study. As such, the proposal is deemed to have received support.

Please be advised that our Board has requested the opportunity to review papers stemming from your research prior to their publication.

We wish you well with your research and look forward to reviewing a copy of your thesis.

Thank you for allowing the Board to comment.

Yours sincerely,

Dr. Catherine Holmes
Principal Researcher, Research Division

Appendix: C Participant Forms

**Department of Rehabilitation
and Aged Care**

Repatriation General Hospital

Phone: 08 8275 110
Fax: 08 8275 1139

Information sheet

<u>(This is for you to keep)</u>

We invite you to participate in a research project about

<u>An exploration of individuals' and their families' experiences and perceptions of transition from inpatient rehabilitation to the community</u>

Why are we doing this research?

To improve the quality of rehabilitation service for inpatients and their families it is important for us to understand your experience when leaving the rehabilitation ward and after when at home.

How will we do this research?

One of us (Deidre Widdall) would like to interview individuals who have been an inpatient of the rehabilitation ward and family members to ask a few questions about their experiences and perceptions of transition from inpatient rehabilitation to the community. There will be three interviews, over a period of approximately 6 months - one in the first week after going home, one after 2-3 months and the last one in the fifth month after leaving the rehabilitation ward. It is expected that each interview will take 30 - 60 minutes. This will enable any changes to experiences that may occur over time to be understood. Interviews will take place in a mutually agreed place that is convenient for you.

What will it mean if you take part in the research?

We want to know what you think about leaving the rehabilitation ward and how prepared you are for going home. We want to hear your stories about your experience in the first 6 months after discharge from the rehabilitation ward and suggestions for improvement in preparation for life after discharge. Your identity will be kept confidential and the stories of all the participants of this research project will be used to write a thesis report. It is hoped that publication of results will help rehabilitation services meet the needs of their patients. You do not have to participate in this study, participation is voluntary – this means you can say NO.

If you agree to participate the interviews will be audio-taped to ensure we accurately capture your story. These tapes will be kept in secure storage and only the Research Team will be able to listen to them. After five years, the tapes and paper copies of your stories will be destroyed.

You do not have to tell your story if you do not want to. You can stop at any time. If you find recounting your experiences becomes upsetting then information can be provided about support services. If you decide not to participate that is OK, there will be no consequences for not participating. We will not use your name or anyone else's name in any reports that are published from the interviews.

What we would like you to do.

We would like you to think about the information provided and in the next couple of days you will be asked if you would like to participate. At this time you will be asked if you need any more information to help you decide and you can ask any questions. There will be a consent form to sign. If you agree to participate then Deidre Widdall will phone after you have been discharged from the ward and if still agreeable arrange the time and place of the first interview. We would like you to invite a family member or someone you consider as family to also participate in interviews to tell their stories. You do not have to participate and there will be no change to your care or rehabilitation if do not wish to participate.

Who are the people on the Research Team?

Deidre Widdall	– principal researcher and post-graduate student of Flinders University in South Australia.
Julie Pryor	– first supervisor and Associate Professor at Flinders University
Stacey George	– second supervisor and Coordinator of the Research Component of the Master of Clinical Rehabilitation at Flinders University
Howard Flavell	- third supervisor and Rehabilitation Medicine Specialist at Royal Darwin Hospital

Does the research have ethics approval?

This research project has been reviewed by the relevant Human Research Ethics Committee of the NT Department of Health and Families and Menzies School of Health Research and the Flinders Clinical Research Ethics Committee.

If you have **concerns or complaints** about the ethical conduct of this project you can contact:

(1) The Secretary, Human Research Ethics Committee of NT Department of Health & Families and Menzies School of Health Research, phone: 08 89227922 or email ethics@menzies.edu.au

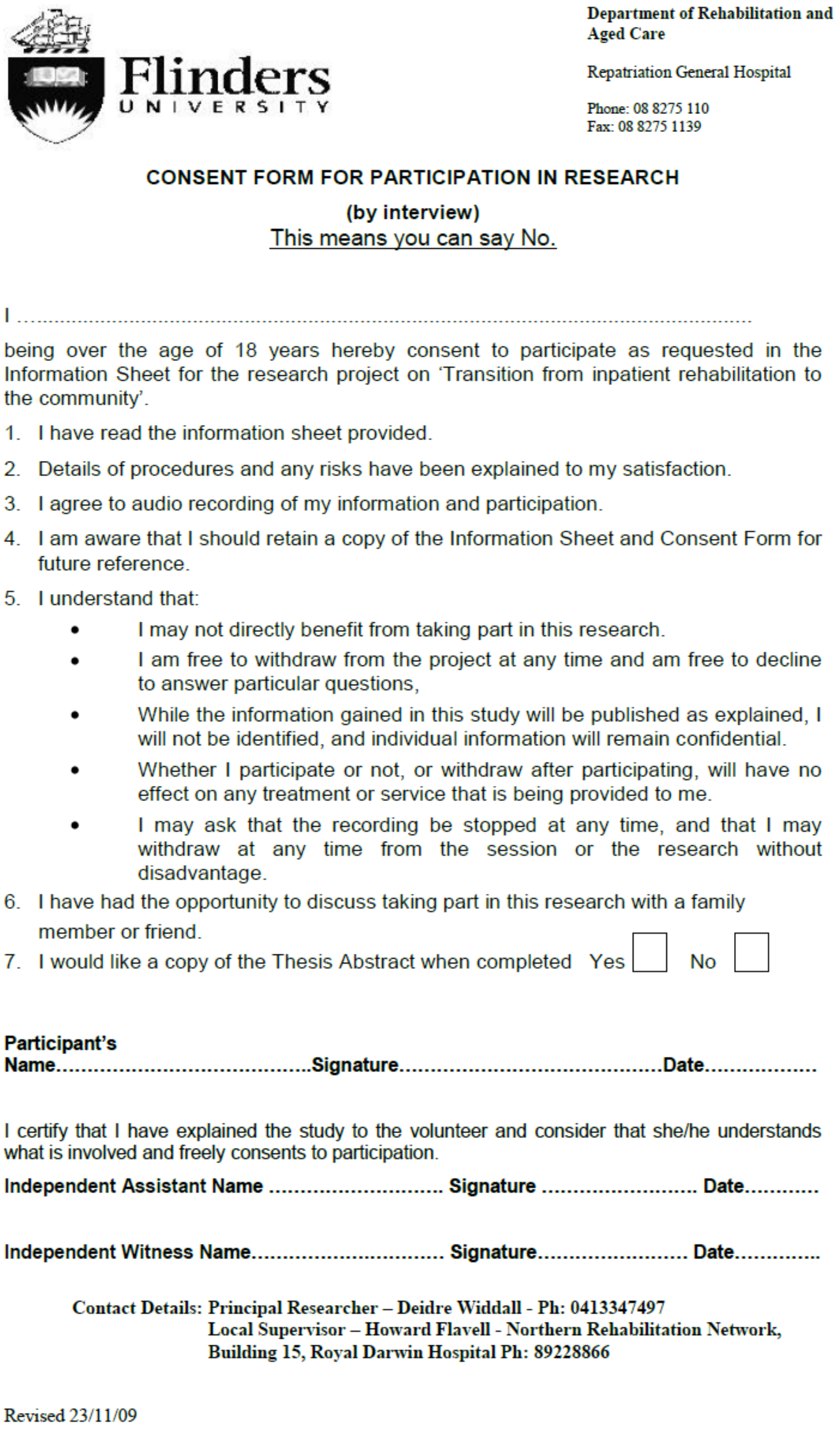
How will the results of the research be reported?

Deidre Widdall will write a Thesis report as a requirement for a Master in Clinical Rehabilitation at Flinders University. A copy of the summary of the thesis can be sent to you once the thesis is completed if you wish.

Need more information? Want to make a comment?

Please contact …Deidre Widdall…..Ph: 0413347497

Contact details
Deidre Widdall, (phone as above)
Assoc Prof Julie Pryor, Ph: 02 98089223
Dr Stacey George, Ph: 82751103
Dr Howard Flavell, Ph: 89228866 C/- Northern Rehabilitation Network,
Royal Darwin Hospital Tiwi. NT 0810



Flinders UNIVERSITY

Department of Rehabilitation and Aged Care

Repatriation General Hospital

Phone: 08 8275 110
Fax: 08 8275 1139

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by interview)

This means you can say No.

I …………………………………………………………………………………………………

being over the age of 18 years hereby consent to participate as requested in the Information Sheet for the research project on 'Transition from inpatient rehabilitation to the community'.

1. I have read the information sheet provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
    - I may not directly benefit from taking part in this research.
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions,
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.
7. I would like a copy of the Thesis Abstract when completed Yes ☐ No ☐

Participant's Name………………………………….Signature……………………………………Date………………

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Independent Assistant Name ………………………. Signature ……………………. Date………..

Independent Witness Name…………………………. Signature…………………… Date…………

Contact Details: Principal Researcher – Deidre Widdall - Ph: 0413347497
Local Supervisor – Howard Flavell - Northern Rehabilitation Network,
Building 15, Royal Darwin Hospital Ph: 89228866

Revised 23/11/09

Appendix: D Interview Guide

Guide for Interview Questions for individuals experiencing acquired disability.

1. Can you tell me about your transition from the rehabilitation ward to home?
2. How well prepared were you for coming home?
3. What concerns did you have before you were discharged?
4. How well prepared did you feel before discharge to cope with those concerns?
5. What are your main concerns now?
6. How well prepared do you feel to cope with these concerns now?
7. Are there improvements to your preparation by the rehabilitation service that could make the transition process easier?
8. What do you think would be the ideal transition from inpatient rehabilitation to the community?
9. What issues/concerns do you anticipate you will encounter/experience in the next 3 months?

Guide for Interview Questions for family member

1. Can you tell me about transition from the rehabilitation ward to home?
2. How well prepared were you for your relative coming home?
3. What concerns did you have before your relative was discharged?
4. How well prepared did you feel before discharge to cope with those concerns?
5. What are your main concerns now?
6. How well prepared do you feel to cope with these concerns now?
7. Are there improvements to your preparation by the rehabilitation service that could make the transition process easier for yourself or for your relative?
8. What do you think would be the ideal transition from inpatient rehabilitation to the community?
9. What issues/concerns do you anticipate you will encounter/experience in the next 3 months?

Collection of Demographic information (at first interview)

Participant with newly acquired disability:-

- Age
- Gender
- Main reason for being in inpatient rehabilitation
- Other health issues
- Total length of stay in hospital
- Length of stay in the inpatient rehabilitation unit
- Characteristics of current living arrangements, eg living at home alone; living at home with 3 family members; living with family member (include reason for not living in own home)

Participant (family member):-

- Age
- Gender
- Relationship to individual with newly acquired disability

Appendix: E Example of Reflective Journal/field note

Field note after First Interview – dilemma clinician versus researcher

First Interview Participant 1 – date 29/10/2010

House is "home built" approx 40 years ago in a semi rural area on large block (5 acres). Appears run down and territory rustic, with not much furniture. (There is a mattress on the floor in front of sofa that P1 is sitting on when I arrive, but apparently this is not where P1 is sleeping – couldn't imagine him getting up and down off floor. P1 lives with other single male friends who share on a part time basis. Some distance from shops and doctor etc, unable to drive at present and dependent upon friends for assistance. We sat outside for the interview at an old table with plastic chairs, lots of mozzies (need to remember repellant next time). P1 was not hesitant about speaking; I was worried that recorder might not be working. At end of interview asked me about medications because webster pack had run out that day. Attempted to arrange one with his pharmacy but scripts needed – his GP not available next day, rang ward and tried to get RN on duty to follow up and promised P1 that I would check that night or tomorrow am what was happening.

1/11/2010

Found next morning nothing had been arranged, no meds on the ward. Subsequently had to get involved in arranging for discharge script to be filled by RDH pharmacy – had not received d/c meds as had gone on leave then was d/c, meds not ready and decision made to send home with one week of meds (in reality was partial week).; P1 not fully aware that he needed to see GP during the week to get scripts and go to chemist. Also found error with d/c letter not including meds listed and had not been dispatched until the Fri any way (same day as interview) so if had gone to GP would not have had record of meds. Info passed onto Registrar and ward RN on the Sat, P1 was to come in and collect d/c meds. Also found that was prescribed Norspan patch for pain as well as Webster and also not supplied.

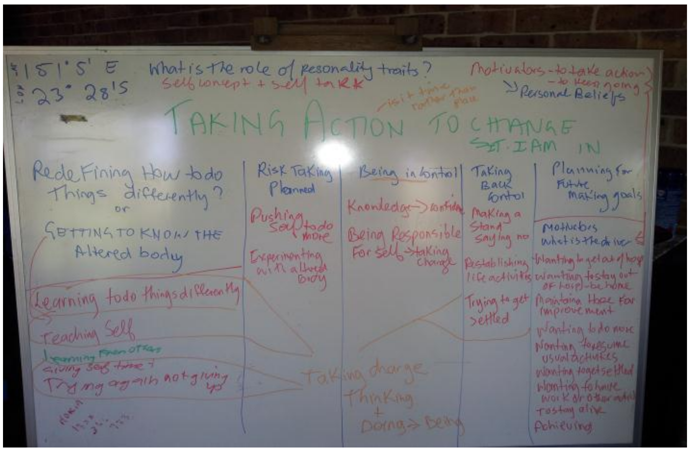
Now a bit worried that I had to intervene and “fix” problems of d/c gaps, and this will affect data.

Appendix: F Data Analysis Activities

Examples of strategies used in early data analysis – development of ideas and understanding of findings depicted via photograph and samples of some of the diagrammatic development.

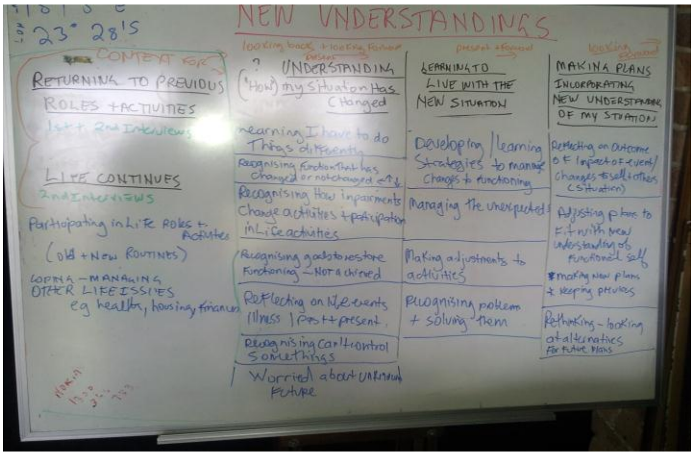
Sorting early codes into groups, after going through transcripts.

Looking for patterns and clumping together related labels/concepts



Using whiteboard to put codes into patterns – ascribing tentative headings for sub-themes & categories.

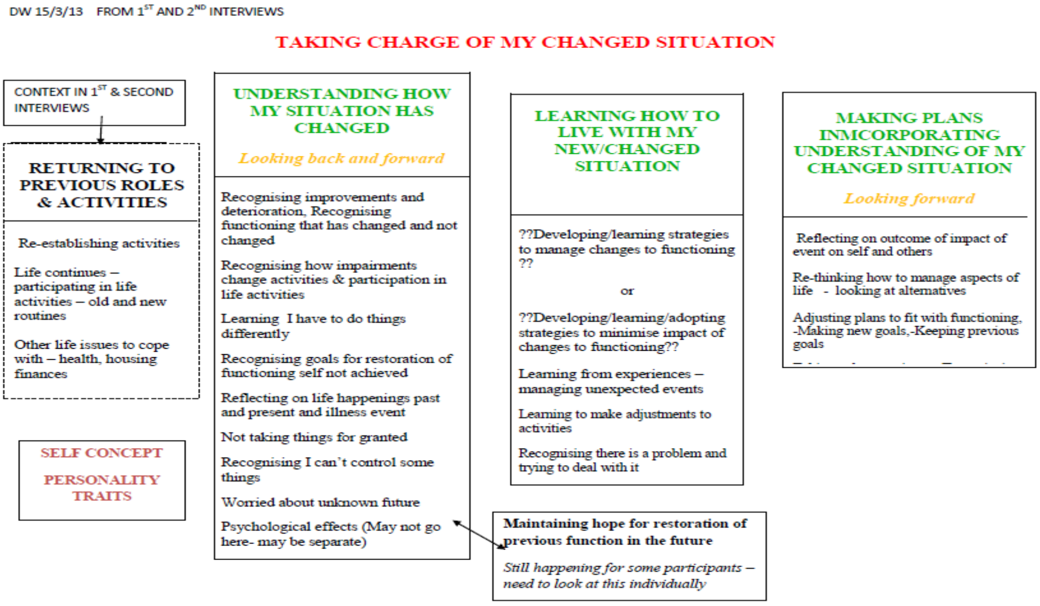
'Taking action to change the situation I am in', later renamed *'Taking charge to restore my*



Using whiteboard to put codes into patterns – ascribing tentative headings for sub themes & categories.

'New understandings', later renamed *'Taking charge of my changed situation'.*

Appendix: G Theme Development



DW 15/3/13 FROM 1ST AND 2ND INTERVIEWS

TAKING CHARGE OF MY CHANGED SITUATION

CONTEXT IN 1ST & SECOND INTERVIEWS

RETURNING TO PREVIOUS ROLES & ACTIVITIES

Re-establishing activities

Life continues – participating in life activities – old and new routines

Other life issues to cope with – health, housing finances

SELF CONCEPT

PERSONALITY TRAITS

UNDERSTANDING HOW MY SITUATION HAS CHANGED

Looking back and forward

Recognising improvements and deterioration, Recognising functioning that has changed and not changed

Recognising how impairments change activities & participation in life activities

Learning I have to do things differently

Recognising goals for restoration of functioning self not achieved

Reflecting on life happenings past and present and illness event

Not taking things for granted

Recognising I can't control some things

Worried about unknown future

Psychological effects (May not go here- may be separate)

LEARNING HOW TO LIVE WITH MY NEW/CHANGED SITUATION

??Developing/learning strategies to manage changes to functioning ??

or

??Developing/learning/adopting strategies to minimise impact of changes to functioning??

Learning from experiences – managing unexpected events

Learning to make adjustments to activities

Recognising there is a problem and trying to deal with it

Maintaining hope for restoration of previous function in the future

Still happening for some participants – need to look at this individually

MAKING PLANS INMCORPORATING UNDERSTANDING OF MY CHANGED SITUATION

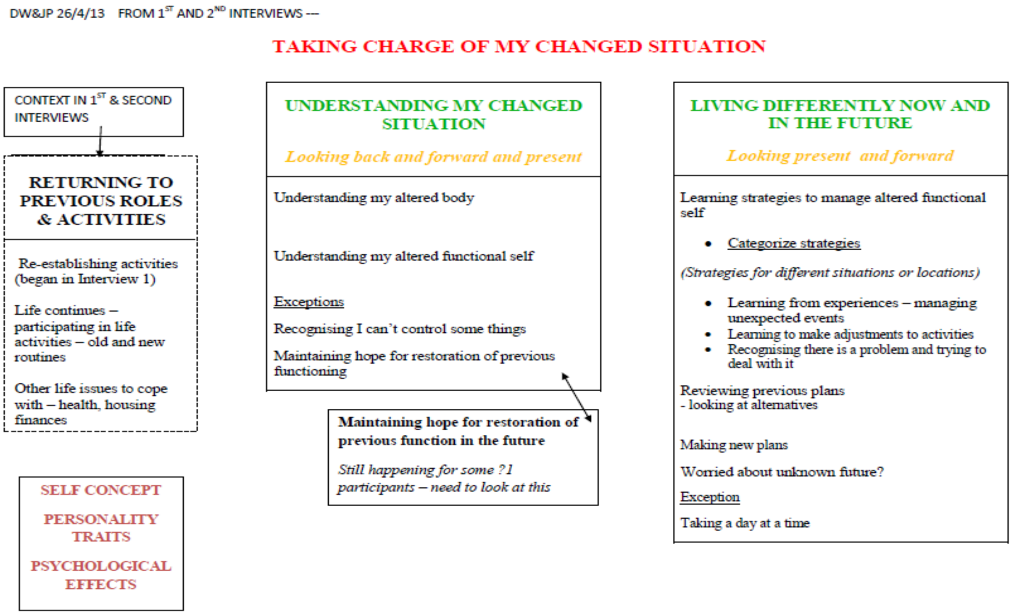
Looking forward

Reflecting on outcome of impact of event on self and others

Re-thinking how to manage aspects of life - looking at alternatives

Adjusting plans to fit with functioning, -Making new goals,-Keeping previous goals

Example of further development of code groupings into diagram of sub-theme and categories for 'Taking charge of my changed situatation'.



DW&JP 26/4/13 FROM 1ST AND 2ND INTERVIEWS ---

TAKING CHARGE OF MY CHANGED SITUATION

CONTEXT IN 1ST & SECOND INTERVIEWS

RETURNING TO PREVIOUS ROLES & ACTIVITIES

Re-establishing activities (began in Interview 1)

Life continues – participating in life activities – old and new routines

Other life issues to cope with – health, housing finances

SELF CONCEPT

PERSONALITY TRAITS

PSYCHOLOGICAL EFFECTS

UNDERSTANDING MY CHANGED SITUATION

Looking back and forward and present

Understanding my altered body

Understanding my altered functional self

Exceptions

Recognising I can't control some things

Maintaining hope for restoration of previous functioning

Maintaining hope for restoration of previous function in the future

Still happening for some ?1 participants – need to look at this

LIVING DIFFERENTLY NOW AND IN THE FUTURE

Looking present and forward

Learning strategies to manage altered functional self

- Categorize strategies

(Strategies for different situations or locations)

- Learning from experiences – managing unexpected events
- Learning to make adjustments to activities
- Recognising there is a problem and trying to deal with it

Reviewing previous plans
- looking at alternatives

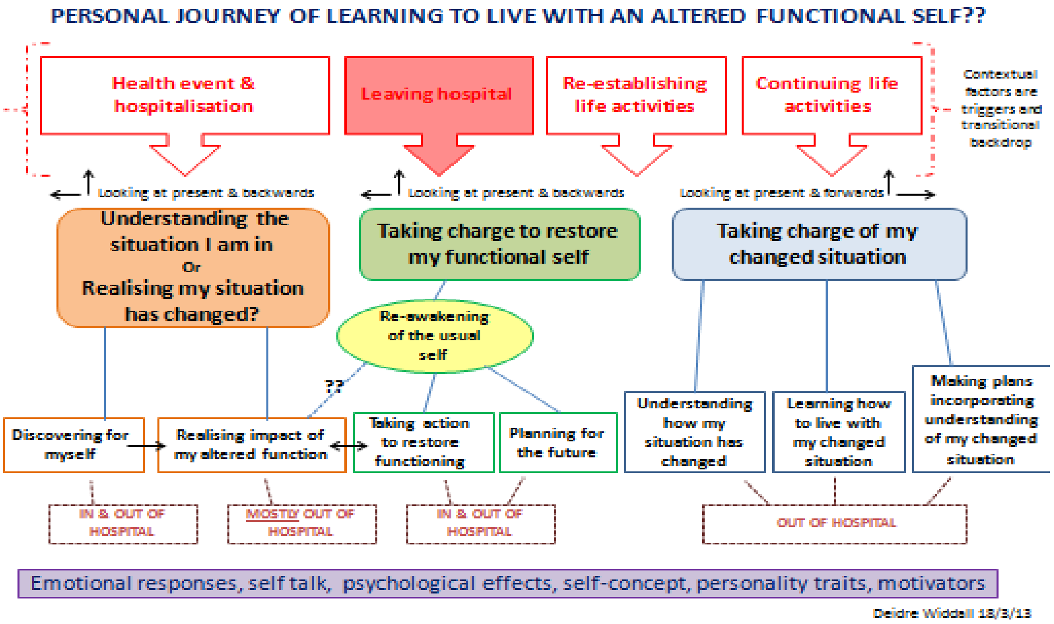
Making new plans

Worried about unknown future?

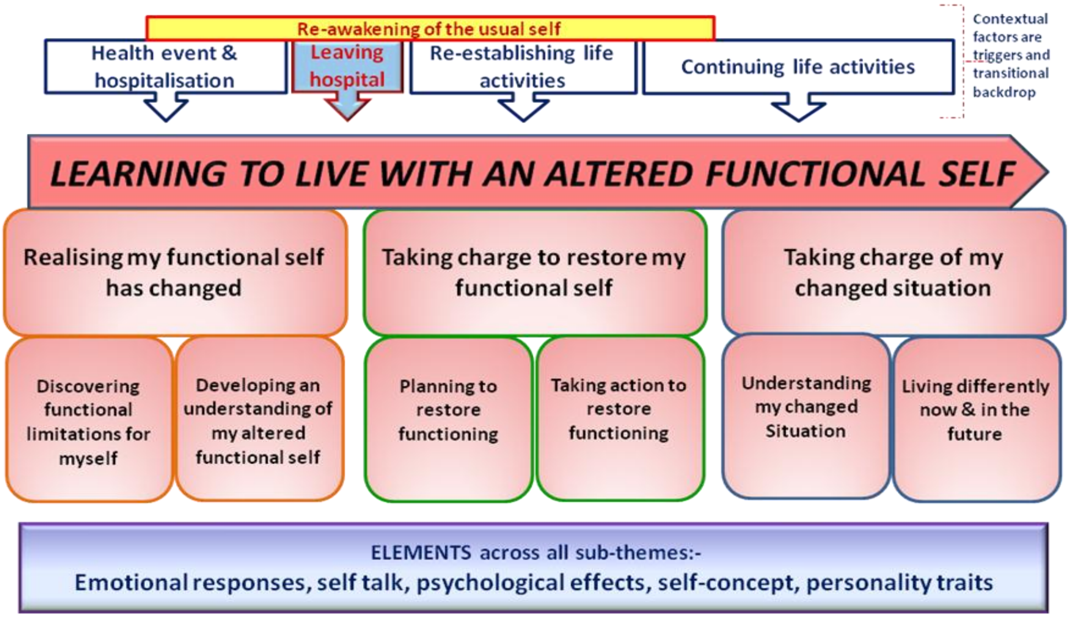
Exception

Taking a day at a time

Later rationalising categories from 3 (above) to 2 in sub-theme 'Taking charge of my changed situation'. Note: contextual and influential elements also depicted



First attempt (18/3/13) of tentative total diagram - to put all elements, sub themes and categories into one diagram and development of first tentative name for overall theme



Development over subsequent weeks (28/4/13) of total diagram - depicting, major theme, sub-themes, contextual and other influential elements, with final words to describe overall theme.- *'Learning to live with an altered functional self.*

Appendix: H Braun and Clarke (2006) 15 point checklist of criteria for good thematic analysis applied to this study

Process and Criteria	*Summary of application to this study*
Transcription 1. The data has been transcribed to an appropriate level of detail, and checked for against tapes for accuracy	*Recorded interviews were transcribed verbatim by a professional transcription service – written transcripts were by checked by listening to recordings and reading simultaneously by the researcher.*
Coding 2. Each data item has been given equal attention in the coding process	*Coding was undertaken systematically by the researcher, labels, categories and meanings discussed & checked by experienced researcher*
3. Themes generated by a thorough, inclusive and comprehensive process rather than from a few vivid examples	*Evidence of theme development was provided and diagrammatic progression depicted all elements identified in the data analysis process.*
4. All relevant data for themes are collated	*Codes from First & Second Interview transcripts were collated into lists, grouped into categories and formed into sub-themes. Items that did not initially fit into categories were kept for later analysis*
5. Themes have been checked and compared with each other and back to the original data set	*During theme development, data categories were compared for similarity and meanings clarified with constant reviewing of transcripts to ensure data context correct and maintained*
6. Themes are internally coherent, consistent and distinctive	*Determining commonality within developing themes ensured they were distinct. Written summaries were used to develop internal consistency and were checked for coherence. Modification and refining occurred to ensure consistency and clarity.*
Analysis 7. Data analysed, interpreted rather than just paraphrased or described	*The researcher thought about the data and attempted to provide interpretive explanations of the experiences described by participants*
8. Data extracts illustrate the analytic claims	*Data extracts used to support the data analysis were included in the presentation of findings and were checked by the researcher & experienced researcher*
9. Analysis tells a convincing and well-organised story about the data and topic	*Diagramming and thematic mapping, helped to conceptualise the complexity of the experiences of participants and refining through writing summaries, assisted in providing an organised representation of the story of the data*
10. Balance between analytic narrative and illustrative data extracts	*The report of the findings includes data extracts which support and illustrate the analysis*

Process and Criteria	*Summary of application to this study*
Overall 11. Adequate time has been allocated to complete all phases of data analysis	*All six phases of the data analysis were applied thoroughly and time was given to enable revision and checking during theme development. Data analysis occurred over approximately 8 months*
Written report 12. Assumptions about and approach to thematic analysis have been clearly described	*The researcher's paradigm and the inductive approach to thematic analysis have been described and demonstrate responsiveness to view of the participants*
13. The description of thematic analysis is consistent with methods performed	*Description of the steps taken followed the 6 phase guide to thematic analysis*
14. Language and concepts used in the report are consistent with the epistemological position of the analysis	*The constructivist paradigm is consistent within the research process and reporting of perceptions and experiences of participants.*
15. The researcher is positioned as active in the research process	*The active involvement in the research process is evident in the audit trail, via use of reflective journaling, recording of the stages in theme development, & the recursive influence of data from Second interviews during data analysis*