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The Meaning of Involvement for Older People in their Rehabilitation after Acute Illness

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The Meaning of Involvement for Older People in their Rehabilitation after Acute Illness

A thesis submitted in partial fulfilment
of the requirements of the University
of Northumbria at Newcastle for the
degree of
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and Education Studies

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Abstract

As the population of people in the UK, over 65, increases and the welfare system moves from a collectivist, towards a consumerist system, involving older people in their rehabilitation and care becomes more important. It is recognised that the effectiveness of practices to increase involvement varies. The reasons for this include the lack of clarity about the meaning of involvement in health care.

The aims of this research were to develop a substantive theory, which explains the meaning of involvement for older people in their rehabilitation after acute illness and facilitates recommendations for health care practice development.

Grounded theory was employed to collect longitudinal data from four older people, their practitioners and support staff, during the participants' rehabilitation stay of around six weeks in an Intermediate Care unit in the UK and at home. Data were collected using recorded, semi-structured interviews and conversations, from December 2008 to November 2009 and were analysed qualitatively.

The findings suggest that involvement in rehabilitation operates through an Involvement Attribute set consisting of two interdependent groups of Involvement Attributes (the psychologically-based and the action-based). Collectively, the Involvement Attributes are: the possession of a Vision, Incentive and Goals, a positive Disposition; a propensity for Cognitive Development; Goal planning, setting and achievement; and Risk Management. To be maximally involved the Involvement Attribute set has to be strong, balanced and with alignment between the two groups.

Involvement in rehabilitation is also related to the type of relationships developed with the health care staff and relatives. Improvements in Involvement Attribute sets require a move away from paternalistic relationships towards the collaborative, partnerships suggested within relationship-centred care. In this way, involvement of older people in rehabilitation is:

> "A joint commitment within therapeutic relationships to determine and be determined in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

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Preface: Thesis Summary

Changes in UK health care demand more patient and public involvement.

Plans to increase patient and public involvement in health care practice have had variable success.

Part of the reason for this variability is the lack of clarification about the meaning of involvement.

Older people can often take longer to recover from acute illnesses than younger adults.

Early discharge from acute hospitals may be effected by physical rehabilitation.

Some older people may not recover fully from their condition.

Older people sometimes have more opportunity than younger adults to become involved in their health care.

Research Question: What is the meaning of involvement for older people in their rehabilitation after acute illness?

Research Aims: To define the nature of involvement in rehabilitation and what this means to the older person and to make recommendations for health care practice development.

Methodology: Constructivist, grounded theory based within symbolic interactionism.

Method: Data were collected, longitudinally, from four older people and health care staff during their approximately six week rehabilitation stay in an Intermediate Care unit. The data were analysed, qualitatively, using grounded theory procedures.

Academic Contribution: Involvement of older people in their rehabilitation after acute illness is:
"A joint commitment to determine and be determined within therapeutic relationships in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

Acknowledgements

I started thinking about the basis of this thesis in around 2003 when my brothers and I were trying to become involved with health and social services over the care of my parents, Esma and Rick, as they became older and worked to stay at home. I was perturbed at how difficult it was to become involved in my parents' care through communication issues with the distant healthcare professionals. This thesis is a direct result of those times and so I thank my parents, yet again, for the firm steer they gave me.

I acknowledge the enormous help given to me by my two, very different supervisors, Dr John Unsworth and Prof. Charlotte Clarke. Their sound advice and encouragement, always facilitative and yet challenging, has raised the level of my work beyond that which I could have attained on my own. I have had a rewarding experience that has prepared me well for new ventures in health care research and teaching.

My second thank you goes to my fellow students from across the globe whose discussions in groups and as individuals over the years, have been part of my development. There are many and I wish them all well. I hope I managed to help some of them as much as they have helped me.

My brother Ian and daughter Jennifer should not go unmentioned as they have encouraged me and taken the interest to read my work and pass comment.

My last thank you goes to my wife, Maria who has helped me so much. Her patience, facilitation, belief and willingness to allow me the individual time to complete this thesis, is something I won't forget.

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.
Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School of Ethics Committee, the University Ethics Committee and the National Research Ethics Service.

Name: **Norman Alexander Stuart Rickard**

Signature:

Date:

Part One

Chapter One: Introduction to the Thesis

Personal Journey to the Research Question

The journey towards the development of the current research has been interesting. My first thoughts were around trying to communicate with social care managers about the rehabilitation of my mother who was unable to relate well to the rehabilitation services on offer. Over a period of months I came to believe that although there was an espoused view, that people should become involved in their rehabilitation, involvement was a complex phenomenon that might be difficult to attain other than at a superficial level.

As the apparent complexity about the meaning of involvement became clear to me, I observed that practitioners were using the term involvement without really understanding its meaning. This was a concern, especially because there has been a policy-driven effort to increase patient and public involvement in health care. A literature review on involvement in rehabilitation, revealed a dearth of literature about the meaning of involvement associated with rehabilitation. Additionally there was a call for research in this area.

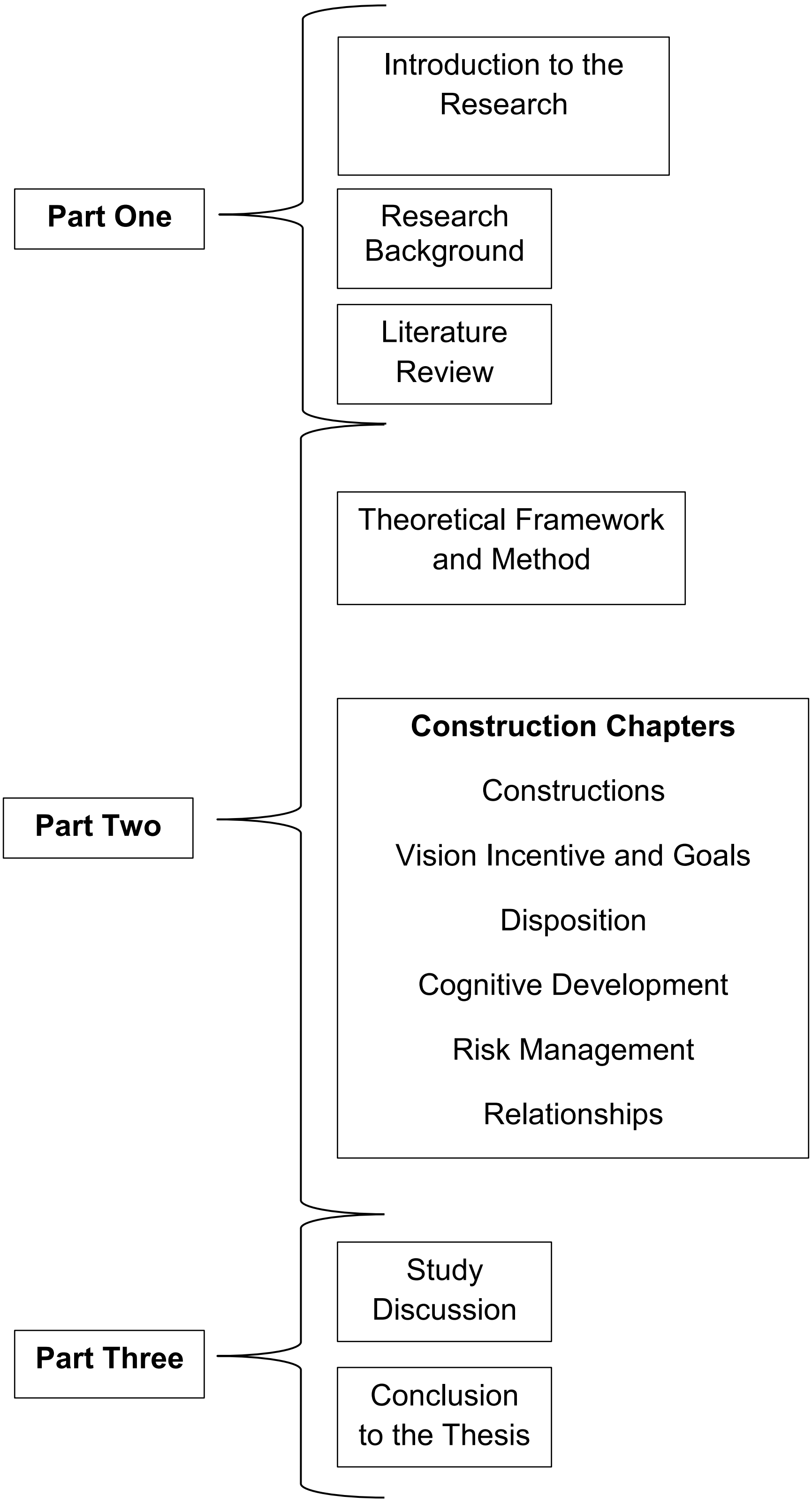
The Global Aims of the Research

The aim of this research was to explore the meaning of involvement in a specific area of health care to develop a deeper understanding of the meaning of the term for the people concerned. This was so that there might be more opportunities for health care staff and people in rehabilitation, to create environments where involvement flourishes with the possibility that rehabilitation outcomes might become richer.

The Construction of the Thesis

The thesis is constructed in three Parts. The first Part has three chapters (including this) containing: The Introduction to the Research, the Background and the Literature Review. The second part contains seven chapters: the Theoretical Framework and Method and the Research Constructions, (six chapters). The third Part consists of two chapters, the Study Discussion and the Conclusion to the Thesis. This structure is outlined in Figure 1.1.

Figure 1.1 A Description of the Construction of the Thesis



Summary of the Chapters

Part One

Chapter One, Introduction to the Thesis

This chapter introduces the thesis and summarises the chapters

Chapter Two, Background

This chapter provides a background to the current research from government policy and health care practice perspectives. Four issues are discussed. Firstly, the research context is discussed to provide an understanding of the area of health care practice that has been researched. Secondly, the move from a collectivist, towards a consumerist United Kingdom (UK) National Health Service is discussed to introduce the reasons why patients and the public are required to become more involved in their health care. This discussion includes a historical overview of significant government policy development. Thirdly, the varying success of these involvement policies is discussed in terms of health care practices. Lastly, the diversity of language around the term involvement and its use is discussed as one of the reasons why the articulation and implementation of involvement policy is difficult. The chapter ends with a statement of the research question and aims.

Chapter Three, Literature review

In this chapter, the diversity of rehabilitation practice research is acknowledged, before this current research is associated with socially-based rehabilitation research that identifies social values within therapeutic relationships rather than more functionally-based rehabilitation research.

This type of socially-based rehabilitation research demonstrates that involvement may require a move from paternalism towards more collaborative therapeutic relationships which are strived for within person-centred care. Person-centred care and related terms are defined and discussed, in terms of current literature and the research aims.

Part Two

Chapter Four, Theoretical Framework and Method

The first part of this chapter discusses the philosophical basis of the current research, in terms of the ontology and epistemology, providing the background for the choice of a relativist ontology and a constructivist epistemology from which to conduct the research. Within constructivism, pragmatism and symbolic interactionism are described and explained. Constructivist grounded theory, based within pragmatism and symbolic interactionism, is then described in detail as the basis for the research methods used.

The second part of this chapter discusses the implementation of a grounded theory methodology to the current research question. The introduction to this chapter describes the data collection design, providing a basis for the choices made in the rest of the chapter. The research setting, an Intermediate Care unit, and the typical progression of an older person through the unit are also discussed.

The data collection process is then discussed in detail. In summary, data were collected related to each of four older people, longitudinally, three times during their rehabilitation stay and once on discharge from rehabilitation. The data collection is summarised in Table 1.1.

Table 1.1 A Summary of the Data Collection Related to Each of the Four Older Participants

Data Collection Times during the Rehabilitation Stay and at home	**Data Collected from Each of the Four Older People and Health Care Staff.**
Period One (around one week)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Two (around one week)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Three (around one week)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Four (at home)	1 Interview with the older person
Total number of interviews and conversations =10x4=40	

Next, a discussion about the approach to, and preparation for, the research is followed by the implementation of the sampling strategy including data saturation and ethical considerations.

The data collection-analysis process follows. In summary, the interview or conversations recordings were transcribed, fragmented, coded and the codes amalgamated in innovative ways. Data collection-analysis used purposive, maximum variation and theoretical sampling techniques alongside constant comparison of the data which continued until conceptual codes emerged. The use of memos, tables and diagrams to aid analysis are described.

Chapter Five, Constructions

This chapter introduces the constructions of the thesis, which are described in six chapters. This first chapter of the constructions describes the background of the participants and outlines the five conceptual categories that came from the data analyses. These categories formed an Involvement Attribute set which operates for each person within therapeutic relationships and relationships with family. The Involvement Attribute set is divided into two groups of Involvement Attributes: those that are psychologically-based and those that are action-based Collectively, the Involvement Attributes are: the possession of a Vision, Incentive and Goals, a positive Disposition; a propensity for Cognitive Development; Goal planning, setting and achievement; and Risk Management. To be maximally involved the Involvement Attribute set has to be strong, balanced and with alignment between the two groups.

Chapters Six, Seven, Eight and Nine: The Involvement Attribute Constructions

These constructions chapters provide evidence for the conceptual analysis of the data for each Involvement Attribute introduced in chapter six, Constructions. The interdependence of the Involvement Attributes is acknowledged but, for ease of study, each chapter demonstrates the composition and position of one Involvement Attribute through an analysis of the differences between each participant.

Chapter Six, Vision, Incentive and Goals

The different Vision and Incentives of the participants are described along with the types of goals. Four types of goals are described (pre-functional, functional, activity-based and social participation). Some participants did not have all types of goals whilst for others, their goals did not match their abilities.

Chapter Seven, Disposition

The ways the components of disposition, hope motivation and enthusiasm, are associated with involvement and how these developed at discharge are discussed. Different types of hope are described, which are: blind hope, unreasonable hope, no particular hope and useful hope. Motivation is discussed as a drive harnessed by enthusiasm which can be directed in different ways.

Chapter Eight Cognitive Development

The way the participants learned, in terms of operant and cognitive learning, is discussed in terms of the older person's rehabilitation stay and after discharge.

Chapter Nine Risk Management

Risk Management is one of the Involvement Attributes, from the Action-based group and is a product of the psychologically-based group of Involvement Attributes. This is discussed in terms of how the participants behaved during their rehabilitation and after discharge, towards recognition of their impairments and their surroundings, how they made decisions and took personal responsibility and control. The way the participants managed risk, moved the locus of control towards them, or away from them towards the health care staff, affected their level of involvement.

Chapter Ten, Relationships

This chapter is concerned with the relationships that each of the participants developed with the staff and relatives during their rehabilitation stay. At the beginning of rehabilitation, all the participants were more reliant on the staff than at the end. However, within this, the participants differed in the way they developed reliance and trust, asked for help and added value to their rehabilitation work. Additionally, different levels of independence were demonstrated by the participant’s divergence from the path prescribed by the staff. Generally, those who were able to have collaborating and partnership interactions were more involved with their rehabilitation. However, this is not a straight forward linear relationship and participants differed in different domains and with different members of staff.

This chapter is concluded by a conceptualisation of involvement into three provinces: the psychologically-based Involvement Attributes, the action-based Involvement Attributes and Relationships. A description of the Theory of Involvement precedes an explanation of the constructions from each participant in terms of the Theory of Involvement.

Part Three

Chapter Eleven, Study Discussion

This penultimate chapter uses the conceptualisation in the last chapter to define involvement for older people in their rehabilitation after acute illness as

> "A joint commitment to determine and be determined within therapeutic relationships in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

Each of the three conceptual provinces introduced in the last chapter are discussed, relating the constructions to the associated published health care practice research and commentary. The constructed meaning of involvement is then associated to the wider social context in terms of the Triadic Reciprocal Causation Model (Bandura 1986) based within Social Cognitive Theory. Using these associations the type of care delivered within person-centred care is discussed as a framework of care able to provide opportunities to incorporate the Attributes of Involvement.

Chapter Twelve, Conclusion to the Thesis

The last chapter includes the academic contribution of the thesis, the achievement of the first aim of the research, to increase the understanding of involvement for older people in their rehabilitation after acute illness. This is followed by discussions that set out the strengths, weaknesses, trustworthiness and limitations of the research.

The next section uses the substantive theory from this current research to discuss the clinical implications of the thesis and recommendations in the light of the thesis and in doing so achieves the second aim of the research. The thesis is concluded with suggestions for further research in terms of testing the substantive theory and developing further understandings.

Chapter Two: Background

Introduction

The meaning of involvement in specific health care contexts, for example in rehabilitation, is elusive and has not been the subject of rigorous research (2004, Baggott, 2005, Cook and Klein, 2005, Staniszewska, 2009, Leplege et al., 2007). There is also confusion in the literature about what involvement in direct care means (Sahlsten et al., 2008a, Entwistle et al., 2008) and other words are sometimes used synonymously with involvement such as participation, for example, Popejoy (2011) and engagement, for example, Clancy (2011). By investigating the meaning and constructing a deeper understanding of involvement within rehabilitation, this current research seeks to reduce this elusiveness, increase clarity and inform the involvement debate in the area of direct care.

Conceptualisation of the term involvement is made difficult because “Involvement” is a human construct which does not have a physical form that can be studied easily and directly, using empirical research. In symbolic interactionist terms (Blumer, 1969), discussed in chapter four (Theoretical Framework and Method), the term involvement has not been reified in either a lay or a professional sense within specific health care contexts, such as rehabilitation (Eldh et al., 2010). To assist discussion, an initial conception and type of involvement considered in this thesis will be discussed, before going on to construct the meaning through research.

Tritter (2009) has defined patient and public involvement as the

> "Ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development organisation and delivery of health services" (p276).

Analysing this definition, Tritter (2009) recognises that there are different types of involvement concerned with planning, delivery and evaluation. Patients and the public are aggregated into one group differentiating them from staff in the health care services.

Interpreting the Tritter (2009) quote above, the term "apply their priorities" relates to the patients and the public *doing* something for which there would have to be opportunities to "draw on their experiences." However, Tritter's (2009) conceptualisation of patient and public involvement does not go as far as to demonstrate the meaning of involvement for the older person.

In this current research, each participant had the opportunity to "apply their priorities" and "draw on their experiences" during their rehabilitation stay. This was done by, for example, making decisions and suggestions about the advice given to them by physiotherapists, occupational therapists, nurses and support workers. Participants could also apply their priorities and draw on their experiences, indirectly by giving feedback, through practitioners, about their care and rehabilitation. This facilitates opportunities for pro-action, for example, in preparation for the next day, and for reaction, for example, through the assessment of personal progress.

The background to this research discusses four main issues. The first is related to the research context, concerned with the rise in the population of older people in the United Kingdom (UK) and the development of relevant health services that meet the needs of this population group. Services for older people who have functional dependence are targeted. The second issue discusses the move from a collectivist towards a consumerist health care system in the UK. This includes the UK government policies designed to facilitate patient and public involvement in health care. Moving into the area of health care practice, the third issue is concerned with the variable success of these policies. The fourth issue discusses some of the reasons for this variability concerned with the diversity of language surrounding involvement and its use in health care, demonstrating the need for clarification from the patients' perspective.

The Research Context

In 2005 more than 11 million, 18.7%, of the UK population were of state pension age or over. This population is projected to rise to around 13 million by 2021 and will continue to rise (Office for National Statistics, 2006). The increase in health care services required by this group is complex. Although a rise in the population of older people will require an increase in health services to this group, this rise will not necessarily lead to a proportionate increase in health burden on society. This is because the societal health burden is not only placed on those between 16 and 65 by those who are below 16 and 65 and over. This will be more evident as fixed retirement ages are abandoned and medical advances continue to take place (Laing and Buisson, 1996). Conversely, the health burden on society will increase as older people, who may have multiple pathologies, require longer recovery times than other, younger adults (McCormack, 2001).

One of the services that have been developed to assist in this situation, by offering an alternative to acute health care provision, is the Intermediate Care service. This is designed to promote independence and autonomy through the rehabilitation of older people after acute illness. The aim of this service is to reduce the potential increase in the unnecessary use of acute hospital beds, commensurate with the demographic changes in the population of the UK discussed above. The service offered in inpatient Intermediate Care units is care and rehabilitation, of around six weeks in duration, provided after acute episodes of illness (Unsworth, 2005). Patients can be admitted to Intermediate Care services from home (hospital avoidance) or from a hospital ward (early discharge), forming a partnership between acute care, primary care and social care (Department of Health, 2000). The participants of this current research were subject to discharge facilitation from hospital *via* an Intermediate Care unit. As the participants became medically stable, they started a rehabilitation programme, led by physiotherapists and occupational therapists, and care, led by nurses. This rehabilitation programme provided the context for the capture of data, in the form of recorded interviews and conversations from the patients and staff, which facilitated the construction of a deeper understanding of involvement.

The rehabilitation programme in the Intermediate Care unit is based on work that is significantly different from that of acute health care. In acute health care, interventions delivered by health care staff often have the intention of being curative, for example the administration of intravenous antibiotics. Some of these healthcare interventions are highly effective and have, for example, a low “Number Needed to Treat” (NNT). The NNT is an epidemiological measure of the effectiveness of health care interventions (Suissa, 2009). If a treatment was fully curative, for everyone, then the NNT would be one. Other interventions have a much more variable efficacy and so have a higher NNT. In this situation, the success of the intervention, cure, is more dependent on the individual person and their relationship to the intervention and illness, for example treatments for fibromyalgia. In these cases, an outcomes effectiveness model (Titler et al., 2010), which places emphasis on the relationship between the intrinsic characteristics of the patient, the interventions and the outcome, is more useful.

Older people, in rehabilitation after acute illnesses are often suited to effectiveness model of intervention, as they move from dependence to independence. This effectiveness of treatment approach has been discussed as a way of taking those who cannot be “cured” out of the medical system, to make way for those who can be cured, which reduces the sense of failure in this respect (Wilkin and Hughes, 1986, Nolan et al., 2006). However, the creation of this group is still subject to markers of success and failure. This is demonstrated through definitions of successful ageing such as, the avoidance of disease and disability, high levels of physical and cognitive functioning and the active engagement with life (Holstein and Minkler, 2003). If these definitions were applied to some older people in rehabilitation after illness, their care and rehabilitation may still be deemed to be unsuccessful. Additionally, success or failure may depend on the measurement tool and whether the measurement was from an organisation perspective, the staff's perspective or the patient's perspective.

Nicholas et al.(2003) moved the outcomes of health care away from a binary, success and failure, system suggesting that there were three types of outcome. These were: those focussed on improving health and wellbeing; those focussed on the maintenance of health and wellbeing, in the widest sense; and those focussed on the process of service delivery. Glendinning, et al (2006) went even further, defining health outcomes as

> "The impacts or end results of services on a person's life" (p2).

These, more wide-ranging definitions, make it increasingly difficult to measure an individual's rehabilitation outcome, based on the work of the health care staff alone, and facilitate measurement of outcomes based on those identified by the service user.

This understanding of health care interventions also facilitates a consideration of rehabilitation as a psycho-social experience (Adams and Gardiner, 2005) that affects people's lives holistically. This understanding is also useful to those people requiring rehabilitation, who may not return to absolute independence and have the opportunity to develop deeper therapeutic relationships within the health care system. These deeper therapeutic relationships facilitate opportunities for people to become involved and learn about their impairments, and how these affect them personally (McCormack, 2001). This contrasts with the level of involvement possible during acute or short term illness.

This current research considers the meaning of involvement within this continuous and inclusive, physical and psycho-social milieu, created by the organisation, the Intermediate Care staff and the participants. All the participants played a part in their rehabilitation in a way that meant something to them. The differences between the participants were used to develop a deeper understanding of involvement through a research focus on the interdependence of service delivery by the staff and service reception by the participants.

Strategic Changes in the Welfare Management of the United. Kingdom (UK) Population

A central theme of current NHS reform is concerned with a move along a collectivist-consumerist continuum towards consumerism and an individualist approach to health care (Lupton et al., 1998, Giddens, 2000, Fox, 2003, Calnan, 2010). This is discussed here by considering three issues. Firstly, the collectivism of the early National Health Service and its limits, secondly, the move from collectivism towards consumerism and its limits, and thirdly, the policy-driven facilitation of an increase in patient and public involvement in health care.

The Collectivism of the Early National Health Service

At its inception in 1948, the National Health Service (NHS) was conceptualised as a service: free at the point of consumption, advocating universality and equality of citizen access, where all received the same treatment, at the best level the economy could afford (Marshall, 1965). This was paid for by general taxation. The assumption was that health care, provided to the population in this way, would improve the health of the nation and so increase self-reliance and individual decisional control over health issues (Gallant et al., 2002). At this time, the state had much more control over the NHS than currently, and this was mediated by the medical profession, who exerted clinical judgement in the use of resources (Lupton et al., 1998). The principles of this collectivist model of health care provision were set out in the Report of the Inter-Departmental Committee on Social Insurance (The Beveridge Report) in 1942.

The third principle, on which The Beveridge Report (1942) was based, included a statement of co-operation between individuals and the state in terms of welfare.

> "[Policies of social security] must be achieved by co-operation between the State and the individual, with the state securing the service and contributions."[The state] should not stifle incentive, opportunity, responsibility; in establishing a national minimum, it should leave room and encouragement for voluntary action by each individual to provide more than that minimum for himself and his family" (p6-7).

However, the all-encompassing National Health Service (NHS), set up through the National Health Service Act 1946, was not flexible enough to manage the healthcare needs and wants of individuals (Schafheutle, 2008). Advances in health care treatments have meant that health care costs have risen disproportionately since that time (Roberts, 2008) and some of the original concepts have been blurred, for example, free at the point of consumption has been blurred by direct charges to the public for medical prescriptions, spectacles and false teeth (see Schafheutle (2008) for a discussion of this).

Limits to, and Constraints on, the Collectivist Approach to UK Health Care

If all have equal access and are treated the same, within limited resources, as part of the public good, the type and quality of those services which comprise the public good is a national issue. Individuals may wish to be treated in ways not provided by the state, but if the state provides all the health care, within the means of the majority, and there is no way for the public to voice their requirements of a health care system, then, using Hirschman's Treatise on Exit, Voice and Loyalty (Hirschman, 1970), loyalty to the system may be the only feasible option. In the absence of a mechanism that facilitates some kind of involvement, that has an effective impact there is reduced opportunity for change in the way patients would choose. The move away from collectivism towards consumerism within the NHS facilitates more opportunities for members of the public to "voice" their dissatisfaction and influence the development of services.

The Move towards a Consumerist Approach to Health Care and its Limits

In the collectivist model of the UK, NHS patients had a right to health care but not to the level of treatment and care they might choose. It was argued that the collective right to health was difficult to sustain because of the difficulty of defining health in a way that had the same meaning for all and was affordable by the state (Lupton et al., 1998). This was different to other public rights, such as civil and social rights, which are based on virtue and justice and not linked to rising costs. It was also thought that the strength of the welfare state had created dependency rather than self-reliance (Croft and Beresford, 1992).

The consensus that it was the role of the state alone to ensure social and economic prosperity, declined after the late 1970's and the role of the state in the UK, including the NHS, receded (Croft and Beresford, 1992). The call for a consumerist approach to health care was made formally in the Griffiths report (1983) and was enshrined in law by the NHS and Community Care Act (Department of Health, 1990). This divided state health care provision into purchasers, purchasing health care at a regional level, and providers working at hospital and community level.

The movement towards consumerism, from collectivism, in health care, developed in the NHS based on a provision of choice and increased opportunities to maximise the use of resources using different health care providers. The creation of the intra-state market, described above, paved the way for non-state organisations such as voluntary, not-for-profit and private organisations to compete with statutory bodies for the provision of health care services. For example, hospital services were put out to tender in some hospitals (Taylor, 2000).

This consumerist position considers the individual, rather than the population, as the unit of function and, as a result, improvements in health care become an issue for the individual. However, although the extreme of a state-run, all-encompassing health service was thought to be difficult to sustain, it is also difficult for the public to take the position of an independent, knowledgeable consumer. The consequences of this limit the extent of a consumerist approach to health care within a welfare state (Titmuss, 2004).

Older people may know a great deal about their impairments, from an ability perspective, but little about their physiological conditions, the options available and the resources required to reduce, alleviate or circumvent health problems. This is an important knowledge gap between the older people and their health care staff and managers. It is this knowledge gap and the time that may be available for action to obtain information, which demonstrates some of the limits of consumerist-driven health care (Titmuss, 2004).

In the collectivist system, older people put their trust in the NHS staff and system to assist in making health care choices. However, as a good consumer, obtaining the knowledge required could mean resorting to independent advice. Notwithstanding the availability of information on the internet and other sources, this advice would normally be obtained from an expert independent of the system; a medical professional. If the only advice available is from medical practitioners who might provide or give access to health services, it might make it difficult for an individual older person to treat the advice as independent and without obligation. This obligation might reduce opportunities to make different choices from the health care on offer. Lastly, even if the older person had the knowledge, the individual may not have the human agency to act (Bandura, 1989). Once again, using Hirschman's treatise (1970), the health consumer, without the means for private health care and the human agency to procure it if it were available, may not be able to "exit" the system. For individuals and groups to become more involved, there has to be effective mechanisms that facilitate the individualisation of health care.

Policy Driven Changes Designed to Increase Patient and Public Involvement in Health Care

One of the first policy-driven attempts at making the health care service accountable to the patients was the Patients' Charter (Department of Health, 1991), which set out patient rights and standards, but was not directly concerned with the level of quality (Smith, 1995, Crinson, 1995). In addition, there was no mechanism for redress if these rights were abused and so the Patients' Charter had little direct impact in making health services accountable to patients as individuals (Herriott and Morris, 1994). The Patient's Charter, revised in 1995, was integrated into a new charter in 1997 and discarded when the NHS plan (Department of Health, 2000) came into force. The historical point of the Patients' Charter was not in the content, though this did have some useful effects (Ryland, 1996), it was in the demonstration of the change in the NHS towards the consumerist end of the collectivist-consumerist spectrum of health care delivery. Since that time there has been various other legislation enacted, which has wrestled with finding a workable partnership that marries a consumerist approach to a fundamentally collectivist health service, still largely free at the point of consumption (Tritter, 2009). The New NHS, Modern and Dependable (Department of Health, 1998) and Patient and Public Involvement in the New NHS (Department of Health, 1999) sought to find a “Third Way” providing some of the advantages of consumerism, whilst, refraining from treating health care solutions as commodities. Within the “Third way” The public are expected to take more personal responsibility for the delivery of public services through a partnership with the state (Tritter et al., 2003).

One of the difficulties of moving towards a health service, realistically accountable to the public, is the dominance of health care professionals over service users, based on expertise and control of local and national resources (Hannigan, 1998). This dominance was diminished structurally following the adoption of general management (McGregor, 2006) as a consequence of the Griffiths report (Griffiths, 1983). However, health professionals, particularly those of the medical profession, remained powerful and in many ways only accountable to themselves at a local level (Hannigan, 1998). This was demonstrated in the events at the Bristol Children’s Cardiac Surgical Unit 1984-95, which led to an inquiry and subsequent report: the “Kennedy Report” (Panel of the inquiry team, 2001).

The Bristol events demonstrated an inadequate transparency between organisations and the services delivered to patients providing contemporary evidence for the need for more involvement of patients and the public in their care and treatment. By the time of the publication of the "Kennedy report" in 2002, this need to involve patients was part of the NHS Plan (Department of Health, 2000) and enshrined in law within the Health and Social Care Act (Department of Health, 2001a). However, the Bristol Inquiry Report (Panel of the inquiry team, 2001) went further than the NHS Plan, recommending that patient involvement should be embedded within the structure of the NHS and decision-making processes. The report demanded a framework for a partnership between health care professionals and patients.

After this, the NHS Reform and Health Care Professions Act (Department of Health, 2002) abolished the more distant Community Health Councils (CHCs) (185) in favour of more local (572) patient forums. These forums, one associated with each Trust and Primary Care Trust (PCT) in the UK, was set up under the auspices of the independent, non-departmental public body, the Commission for Patient and Public Involvement in Health (CPPIH). In addition, the Patient Advisory Liaison Service and Independent Complaints Advisory Services became available to patients locally. The CPPIH was disbanded in early 2006 when patients forums were replaced by 152 Local Involvement Networks (LINks) associated with localities rather than institutions. Finally, the NHS Act (Department of Health, 2006) came into force in Nov 2008. This Act consolidated the Health and Social Care Act (Department of Health, 2001a) and made it a legal requirement for health organisations to make active arrangements to involve patients and the public in health care arrangements. Additionally, guidelines were produced (Department of Health, 2008) about

> "Who they [organisations] need to involve and what they need to do to deliver better involvement practices" (p11).

As this change in responsibility occurs, health care responsibility moves away from a national concern, to the concern of individuals and communities. The state no longer provides a safety net, in times of trouble, but a springboard of opportunity for development (Hale et al., 2004).

The change in responsibility has been taken up by successive governments as "The Third Way" between consumerism and collectivism summarised as providing opportunity but expecting citizen responsibility in welfare (Giddens, 2000). Under these conditions, health care is a combined responsibility of practitioners and citizens who, as a group, should become better mobilised to look after themselves (Williams and Grant, 1998) in the knowledge that the hospital system cannot be relied on to do everything for the patient. The aim is to

> "Maximise the control and choice which individuals can exercise regarding their health and health care" (Christensen and Hewitt-Taylor, 2006).

This is further exemplified by the government's current plans to change the UK welfare system outlined in the consultation paper "21st Century Welfare" (Department of Work and Pensions, 2010) which set out to reform the welfare state in the same areas as outlined in the "Beveridge Report" (Beveridge, 1942), adopted by the labour government in the late 1940's.

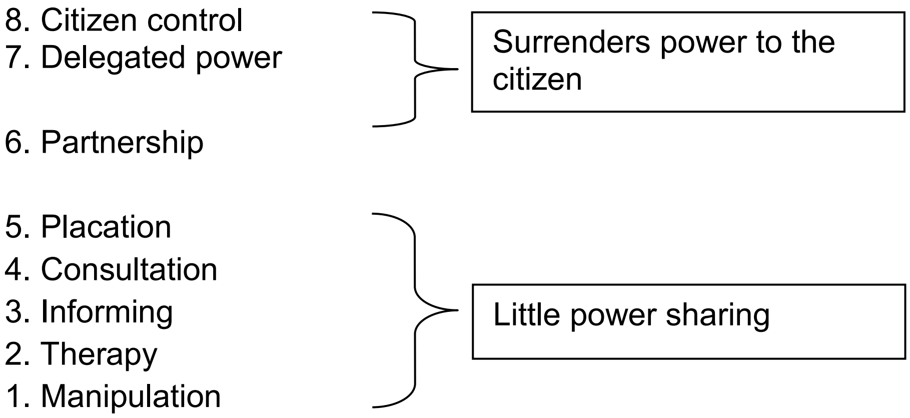
There has been an abundance of legislation to introduce and embed consumer involvement in health care. This policy-driven approach has altered structures so that there are mechanisms within the health service, designed to create opportunities for patient and public involvement within the broader remit of increasing individual responsibility for health care. However, the level of change that policies, alone, can have on the culture of the NHS is arguable.

Helping and Hindering Forces in Effecting Policy Driven Involvement Mechanisms in Health Care

Prior to the NHS there was a history of substantial volunteerism (Tritter et al., 2003). When the state took control of the nation's health there was an increase in professionalism leading to a reduction in the roles of non-professionals and lay and elected managers. This was because these groups found it increasingly difficult to be credible (Lupton et al., 1998). The power differential, between the medical profession and others (McGregor, 2006), seems to be a main issue in the increasing passivity of non-medical involvement (Hogg, 2007). This power differential is associated with the possession of knowledge and information about patient's illnesses, the access to NHS services, the use and choice of resources and clinical decision-making (Calnan, 2010, Titmuss, 2004).

Power differentials, between the dominant group and the citizen, have been analysed (Arnstein, 1969) who suggested that they can be organised hierarchically. This hierarchy is presented as an eight rung ladder which relates citizen participation to the level of power citizens possess. The ladder moves from degrees of citizen non-participation, through tokenism, to citizen power (Figure 2.1).

Figure 2.1 Arnstein's Ladder of Citizen Participation



8. Citizen control
7. Delegated power

6. Partnership

5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

For an individual to be involved directly, proactively and reactively in an ideal power-sharing arrangement, a partnership relationship is required (Figure 2.1). The first five rungs of the ladder involve little sharing and the top two rungs of the ladder surrender power to the citizen. The theory base behind Arnstein's (1969) participation ladder is not discussed in her short paper. Moving up or down the hierarchical ladder seems to be based on the taking of power by the "have-nots" at the expense of the "haves" (Tritter and McCallum, 2006). In these terms, a partnership in rehabilitation with older people and the health care staff would require a change in the *status quo* which

> "Enables them, [the have-nots, in this case older people in rehabilitation] to negotiate and engage in trade-offs with the traditional power holders" (Arnstein 1969) (p217).

Arnstein's (1969) model of citizen participation provides a structural position (Donabedian, 1980) of partnership but does not discuss the process by which this can be attained, or the meaning of the construct of involvement used by the people within a partnership. The top-down policies of the UK government, discussed above, have also provided structural mechanisms that increase the opportunity to move towards partnerships in health care relationships. Partnerships provide opportunities for a new kind of involvement with health care staff. However, the operation of these mechanisms to increase partnership and involvement in health care has been variable.

It has been reported that better outcomes occur when patients are involved (Stringer et al., 2008a, Peterson et al., 2008). Additionally, Stringer, Van Meijel et al. (2008a) in their literature review, report that

> ”User involvement leads to improved satisfaction, a higher quality of care, better health, greater treatment compliance and a safer environment for patients and care providers” (p679).

Involvement of patients, in the planning and development of health care, has also been reported to have contributed to the improvement of services and changes in attitudes within organisations (Staniszewska et al., 2008).

However, the policies have not been universally successful. Stringer, Van Meijel et al (2008a) also suggest that, in mental health services, health care providers may not be inclined to involve patients, whilst other research shows that service user involvement is used to reinforce the position of the dominant discourse (Stickley, 2005, Rose, 2003). Croft and Beresford (1992) discuss some ways involvement can be used by health care professionals who use the dominant discourse, to divert or limit effective action. These include delay, co-option of representatives into the dominant discourse, the involvement of the public to legitimise decisions and making involvement tokenistic by ignoring arguments put forward by the public. Additionally, it has been reported that doctors and nurses may accept the legitimacy of patient participation in decision-making about their own care, but only in a consultative role and not in the decision-making process (Gagliardi et al., 2008, Solbjør and Steinsbekk, 2011, Henderson, 2003). Chambers, et al (2003) also cite many examples of reasons for failure to involve the public, including, poor methods, lack of commitment and failure to act on the results of research. In these situations staff seem to have managed the pressure to increase involvement to maintain the *status quo.* Under these conditions, it is a challenge for service users to become equal partners, prospectively involved in their treatment and care (Rose, 2003) beyond the superficial.

In some ways there are indications that the public are ready for this challenge. The public are more aware of their rights, have a desire for choices (Kennedy, 2003) and there is a reduction in deference to authority (Hewitt-Taylor, 2003). Mistrust in health care delivery may exist in the light of, for example, the report into the care and treatment of patients in Stafford, (Francis, 2010), and challenges in the court (Dyer, 2004). Additionally, there are some places where involvement of patients is demanded, for example, in

the employment of user groups such as the Shaping Our Lives Network by health care providers (Croft and Beresford, 1992). In these circumstances there has been an increase in the power base of the service user.
In other ways the public are not ready for involvement in their health care. The “Shaping Our Lives Network” occupies an isolated and special position, acquired by service users *after* their dealings with health care practitioners. Involvement may be more difficult in direct care, when care is taking place. Older people and their families often take a traditional, collectivist view of health care and fail to recognise the need to, or be unable, to act as an increasingly informed partner. (Croft and Beresford, 1992, Gagliardi et al., 2008).

The traditional relationship between patient and health care staff, particularly the medical practitioner, assumes that knowledge of the patients’ condition lies solely with the practitioner (Kennedy, 2003, Parsons, 1952, Coulter, 2011). Patients are seen as receivers of health care and decisions made about health care are made by medical practitioners based on their knowledge of the condition and the resources available. This approach leads to a paternalistic relationship with the patient (Deber, 1994) and is defended, historically, on the basis that patients, who are ill, cannot be expected to make decisions about their health (Kennedy, 2003). However, it has also been reported that a traditional approach centres care on the preferences of the clinician (Beach et al., 2006).

In terms of specific, direct patient care, this traditional approach to health care relationships seems to suit some patients. Older people are reported to be less likely to want to be involved in treatment decisions than their younger counterparts (England and Evans, 1992, Strasser et al., 1992) and have lower expectations of health care interventions, which reduces involvement (Hsu and McCormack, 2010). As a result, some authors, for example Allen and Redman (1996) concerned with cardiac rehabilitation, consider that the way to improve effectiveness in rehabilitation is by adapting rehabilitation programs to meet the needs of older people specifically. However, the needs of different patients may vary widely. These differing needs were demonstrated within more general post-acute rehabilitation by Lund, Tamm et al (2001) in their study of 57 hospitalised patients who, using a descriptive design and semi-structured interviews, found three types of patients. These were: relinquishers, who relinquished responsibility for decision-making about the planning of rehabilitation to the staff; occasional participants and participants who seemed more fully involved with the planning decision-making. In the same study, 50 health care professionals were asked about the strategies they used to encourage participation and they reported that they did not vary their approach with the different types of patient. This suggests that the staff were insensitive to the different types of patients in rehabilitation and were unaware of their potential readiness to be involved.

Palmadottir (2003), in her descriptive study of 20 patients in occupational therapy, supported this argument reporting that the participants were “quite satisfied” (p164) being led by the occupational therapist. However, Florin, Ehrenberg et al.(2008) found that preferences for leadership were conditional on the situation, reporting that patients often preferred to adopt a passive role, for example, in the treatment of pain and breathing issues. These same patients preferred a more active role related to activities and discussions. Other studies also show this mixed trend. Some studies suggest that patients are interested in playing an active role in their health care (Ende et al., 1989, Degner and Sloan, 1992) while others suggest patients have no interest (Deber and Kraetschmer Irvine, 1996, Macleod and Macleod, 1996).

To measure participation Lenze et al (2004a) devised the Pittsburgh Rehabilitation Participation Scale (PRPS). The PRPS was devised with data from 242 post-acute rehabilitation patients and has been used by Lenze et al (2004b) to categorise rehabilitation patients as good participators, occasional poor participators and frequent poor participators. In the Lenze et al (2004b) study, poor participation was associated with poorer rehabilitation outcomes and longer lengths of hospital stay. In their conclusion this research team suggested that poor inpatient rehabilitation participation and its antecedents deserve further attention.

This attention is necessary for a variety of reasons. Firstly, there may be times when patients are ill-equipped to participate. Examples of being ill-equipped include poor health literacy, (Levasseur and Carrier, 2010, Coulter, 2011) differing knowledge bases (Fitzpatrick et al., 1987, Cahill, 1996, Florin et al., 2008, Millard et al., 2006) and problems of ageing such as poor hearing or eyesight (Coulter 2011). However, some patients may not want to make the effort of participation (Bastiaens et al., 2007) which equates to the relinquishers in the Lund et al (2001) study discussed earlier. Williams and Grant (1998) regard this latter point a fundamental issue that needs to be addressed if the power balance is to be moved towards the patient from the health care staff.

Secondly, it is difficult to see how older people in rehabilitation, if we believe them to be the “have-nots”, could reach the partnership level of Arnstein’s (1969) ladder of citizen participation, without cooperative facilitation (Flax, 1990) with health care staff. For example, older people may need support in self-management in the form of information, education, self-monitoring skills training and behaviour change, to challenge unhelpful beliefs and to manage emotions (Mulligan et al., 2009). The requirement for facilitation makes partnership more difficult when the “have-nots” require health care from those with whom they wish to partner. For example, older people, presenting themselves, or being encouraged to put themselves forward for rehabilitation, do so to receive external help, to return to their former position or to make appropriate changes. This creates a power differential that would seem to preclude partnership in many circumstances.

Lastly, even if the older people had the knowledge and skills required to improve their functional abilities in rehabilitation, many would not be able to help themselves because of their physically weak position and the requirement for medical, physiotherapy, nursing, equipment and other resources. They might not have the power to demand a partnership relationship (Kuokkanen and Leino-Kilpi, 2000). Complexity is added to this situation when older people move from acute care to different rehabilitation units as they improve functionally and their for need for physical care reduces (Wiggins, 2008).

Pilgrim and Waldron (1998) and Henderson (2003) have suggested that a change towards a collaborative partnership in the relationship between service users and health care workers must be led by empathetic professionals who recognise the need for service users to have independence within the health care system. Andrews et al (2004) and Cook and Klein (2005) go further suggesting that to move to a partnership relationship, health care workers need to value patients' perspectives and expertise. Similarly, Jonsdottir et al (2004) entreated nurses who wished to work in partnership with their patients to work with them from a position of their patients' understanding. One of the difficulties of doing this is the diversity of language in the dominant discourses of health care staff.

The Diversity of Language around Involvement in Health Care

If the call for the development of collaborative partnerships, as a way to improve the involvement of patients in their care, is to become more than a desire, the language of the approaches and actions that staff and patients will have to use must become consistent and part of the dominant discourse within health care (Staniszewska, 2009).

A partnership relationship has been a goal in nursing practice for many years (Peplau, 1952, Orlando, 1961) and features a give-and-take attitude and creative mutual exchanges that foster positive health outcomes (Henson, 1997). This assists the service user to "discover their own power" (Montgomery, 1993). Wiggins (2008) used the American heritage Dictionary (2006) definition of partnership

> "A relationship between individuals or groups that is characterized by mutual cooperation and responsibility for the achievement of a specified goal" (p629).

This definition, arguably, incorporates patient involvement in direct care and specifically relates to a relationship with goals. However, there is no mention of how each party might behave within this partnership and so it leaves the behavioural part, the action part, to others.

Participation is a behavioural term, and therefore concerned with action, and is discussed by Tutton (2005) in terms of

> "One who takes part and with what degree of involvement" (p144).

This separates participation from the related term involvement and offers the opportunity for a degree of conceptual measurement as people take part with, supposedly, measurable degrees of involvement. However, others, as reported by Sahlsten (2008) in her concept analysis of patient participation, use patient participation synonymously with involvement. This inability to separate involvement and participation is further noted by Jones et al (2004) who distinguished between private and public participation using the term involvement as an alternative to participation.

> "Private participation refers to the involvement of individuals in their own care and treatment while public participation refers to involvement in decision-making processes concerning service

> planning and delivery, service evaluations and consultations over future service provision" (p94).

There is also some confusion and inconsistency in the literature between the terms empowerment and involvement, which may indicate a naivety in the understanding of these terms. For example, Stringer, Van Meijel et al (2008b) reported that Tilley et al (1999) defined *user involvement* as

> "The extent to which the patient is involved in defining problems and setting targets that constitute the plan of care" (p1125).

However, as part of their discourse in research, (Tilley et al., 1999) defined *empowerment* as

> "The extent to which the patient is involved in defining problems and setting targets" (p679).

Anthony and Crawford (2000) recognise the difficulty of defining service user involvement which

> "Merges and blurs with negotiated care, collaborative care, patient participation and person-centred care" (p426).

Cahill (1996), in her concept analysis of patient participation, suggests a hierarchical relationship between three terms: patient involvement/collaboration, patient participation and patient partnership (lowest to highest). This work was updated (Sahlsten et al., 2008b) but within the updated work, the model case quoted below, seems to lose Cahill's) (1998) hierarchy and does not mention the terms involvement and collaboration.

> "Jenny is a patient in an orthopaedic ward. Since the first day, her primary nurse has regarded Jenny as an equal partner, activating her to participate in all aspects of her nursing care. The nurse starts in Jenny's frame of reference and uses open-ended questions to explore expectations, wishes, and opinions. They also discuss what they

> expect of each other. In their regular talks, they get to know each other and trust and respect develop. Jenny participates in planning, formulating goals, performing activities, and evaluation of her own nursing care. The nurse continually provides information and knowledge adjusted to Jenny's needs and Jenny, in turn, volunteers experiences, values, and beliefs. This generates informed choices and together they negotiate acceptable agreements. Jenny has reached understanding and a sense of control of her own situation" (p7). (*sic*)

However, from these analyses Sahlsten (2008) did report new defining attributes of participation which are significant in light of the move towards consumerism in health. Sahlsten (2008) defined participation as

> "A relationship between the practitioner and the patient, a surrendering of power by the practitioner, sharing information and knowledge and an active engagement together in intellectual and/or physical activities" (p9).

The first attribute is that a relationship between a patient and a practitioner has to exist in some form. The second, a surrendering of power by the practitioner, assumes a power differential and concurs with Arnstein's (1969) view of changes required to move up the ladder of participation towards citizen power (Figure 2.1). The third attribute discusses sharing and within this, is the active engagement of the patient, demonstrating the responsibilities that patients need to take in their own health, in line with the implementation of "The Third Way" (Giddens, 2000).

Many of the attributes of patient participation, discussed by Sahlsten (2008) are also described within eight partnership attributes by Hook (2006). These partnership attributes were described in two sections, those leading to a relationship (professional competence, communication and patient participation) and those leading to empowerment (shared knowledge, shared power, patient autonomy and shared decision-making) (Hook, 2006). This differs from Sahlsten's (2008) work in that Hook (2006) views *patient* participation as one of the precursors to shared power, patient autonomy, shared decision-making and shared information. In Sahlsten's (2008) work a *relationship* is seen as a precursor to patient participation and patient autonomy.

These different definitions are summarised in Table 2.1 and serve to demonstrate the diverse ways terms are used, academically, to describe aspects of health care practice. This comparison of analyses demonstrates that the current position, regarding patient involvement and related terms, is not congruent (Gallant et al., 2002, Sahlsten et al., 2008a). This incongruence makes the constructs (Walker and Avant 1995) difficult to use in health care practice in a way that is understood by all practitioners.

From a symbolic interactionist perspective (Blumer, 1969) the language of involvement in health care, is not yet reified, consistently, in either a lay or a health care professional sense, so that the literary and practice discourses remain diverse. However, attempts to define the use of terms in, for example, concept analyses, demonstrate a professional recognition and interest in process driven approaches to patient involvement in their care. This interest indicates recognition for the need for change. One of the changes required is a development in the language surrounding the term involvement within health care relationships. Forbat, Hubbard et al. (2009) concurred with this when they, concluded that one of the greatest barriers to truly integrating patient involvement into health services, policy and research, is the conceptual muddle with which involvement is articulated, understood and put into action.

Table 2.1 A comparison of the work of Cahill (1996) Sahlsten (2008) and Hook (2006) on the concept analysis of patient participation and Partnership with Patients

(Please read Table 2.1 from top to bottom)

Concept Analysis of Patient Participation Cahill (1996)	**Concept Analysis of Patient Participation Sahlsten (2008)**	**Concept of Partnership (Hook 2006)**
Participation is…	Participation occurs where there is...	A partnership occurs where there is...
A relationship between patient and practitioner and leads to...	A relationship between patient and practitioner and leads to...	Professional competence, communication and patient participation and leads to:
Participation which has the attributes of...	Participation which has the attributes of...	A relationship which has the attributes of
Surrendering of power by the practitioner, A narrowing of the information gap between patient and practitioner Engagement in selective intellectual/or physical activities during some of the phases of the health care process. There must be a positive benefit associated with the intellectual and/or physical activity	Surrendering of power by the practitioner, Sharing of information and knowledge An active engagement together in intellectual and/or physical activities	Shared power Shared knowledge Shared decision-making Patient autonomy

Conclusion

The movement from a collectivist to consumer-based health care system and the concomitant legislation and policies, have provided a policy-driven, structural directive for the “Third Way” demanding the examination of rights and responsibilities in welfare in general. In health care this development requires a change in staff-patient relationships, from a traditional paternalistic relationship, to that of a partnership between patients and health care professionals. This, in turn will require higher levels of patient involvement in their care. Despite the policy directives, there seems to be process barriers against the development of patient involvement in their care and treatment. Some of these barriers are concerned with the poor development of the language from which partnerships may arise. One way of reducing these barriers is to try to develop a deeper, clinically usable understanding of important terms, such as “involvement” which gives rise to the current research question and aims.

Research Question and Aims

Research Question

What is the Meaning of Involvement for Older People in their Rehabilitation after Acute Illness?

Research Aims

The aims of this research were to develop a substantive theory, defining the meaning of involvement for older people in their rehabilitation after acute illness and to make recommendations for health care practice and development.

Chapter Three: Literature review

Introduction

The research question and aims that concluded the last chapter provide the challenge for this third chapter of the thesis; to locate the current research within the diverse body of rehabilitation literature. This chapter discusses how the search strategy was developed, dividing the literature into two groups, the functionally-based and socially-based literature. The current research is located within this socially-based literature concerned with the value-sets of patients and staff and their therapeutic relationships.

Development of the Search Strategy

In order to review the appropriate literature within rehabilitation research, the rehabilitation literature as a whole was considered and the types of rehabilitation literature were identified and summarised in Table 3.1. From this a specific research strategy associated with the research aims and concerned with older people, was developed.

Table 3.1 A Summary of the Classification of the Rehabilitation Research Literature

Rehabilitation Research Concerned with:	
Rehabilitation Effectiveness	**Value-Sets and Relationships**
Functionally-Based (Levels ICFDH One and Two)	
Socially-Based (ICFDH Level Three)	**Socially-based (ICFDH Level Three)**

Considering the rehabilitation research literature from the perspective of involvement, rehabilitation practice research can be divided, initially into functionally- and socially-based research (Table 3.1). The International Classification of Functioning Disease and Health (ICFDH) (World Health Organisation, 2001) which provides a framework to understand health (Gladman, 2008) was used to refine this initial classification.

The ICFDH operates on three levels: the level of the body or part of the body, the level of the whole person and the person in their social context. Within this, rehabilitation after acute illness has two main areas of work, which are operationalised simultaneously. Firstly, there is improvement of physical function (at the ICFDH level one and level two) where interventions take place and the effects can be measured. The efficacy of this type of intervention may be researched using clinical trials, for example, (Cameron et al., 1993) who worked to demonstrate new techniques for speeding up rehabilitation after a femoral fracture. Secondly, there is rehabilitation that socially contextualises the perspective of the person with impairment, incorporating a social adjustment (ICFDH level three) within the process of rehabilitation. This classification is useful as research literature can be divided into those that are mostly concerned with functional improvement and underplay, or ignore, the social, process-based aspects of rehabilitation and *vice versa.* However, the classification is imperfect because rehabilitation professionals are often concerned with the impairments of older people at all three levels of the ICFDH simultaneously.

Socially-based research can be divided into social, process-based research, concerned with improving health care processes and outcomes and that which identifies, or considers the use of, value-sets, such as respect for persons (Table 3.1). The former type is exemplified by Bickers (1993) who, in a clinical trial, demonstrated that verbal encouragement can be used to improve outcomes. This is socially-based because it uses vocal and behavioural gesture, in the form of encouragement to improve outcomes. However, the prime aim of research of this type is to find ways of improving rehabilitation outcomes. In the work of Bickers (1993) the interventions were designed to speed up rehabilitation, using specific socially-based interventions. The interaction that took place between the patients and the staff was not part of the research and so the research is not aligned with this current research. If involvement in rehabilitation is to be more fully understood, then a conceptual understanding of the beliefs and values within a dialogue with practitioners is necessary.

One type of socially-based research that demonstrates this dialogue, is that concerned with decision-making, and, as an extension of this, levels of patient and practitioner accountability and responsibility (Wirtz et al., 2006). Accountability, in health care settings varies. For example, in a surgical theatre when the patient is unconscious, accountability passes mainly to the operating team and perhaps relates to the patient in preparation for, and after, surgery. However, ideas of decision-making, accountability and responsibility between patient and practitioner are more balanced within the effectiveness model of rehabilitative health care. Within longer term relationships decisions about treatment option-sets are revisited as, for example, rehabilitation progresses. This might include decisions about taking appropriate rest, adequate nutrition, or doing extra physical work.

One aspect of these processes is the way decisions are made about interventions in the research literature. This may be paternalistic, interpretative, informed choice or shared with the patients (Charles et al., 1999). In a paternalistic model health care professionals decide what is best for their patients (Redfern et al., 2006, Coulter, 1997). If an interpretive model is used, the practitioner still makes the decision, but takes into account the perceived values and preferences of the patient (Wirtz et al., 2006). Using an informed decision-making model, sometimes called the consumerist model (Wertz, Cribb and Entwistle 2011), the options are explained and the patient chooses from one of the options. Lastly, in the shared decision-making model, at least the patient and the practitioner participate and both agree on the decisions made (Coulter, 2011). In this shared decision-making model the patient requires and accepts some help in the decision-making process (perhaps because of the complexity of understanding required of the condition treatment and prognosis), and the practitioner supports the decision-making process (Cribb and Entwistle 2006).

These models of decision making are written from a practitioner perspective. This may not take into account the patients' perspective in a health care relationship. Kjerski, Nygard et al (2008) demonstrated the use of the patients' perspective in a study to investigate the experiences of participation in occupation during home-based rehabilitation using a sample of three older people. After this longitudinal study, the research group concluded that participation was a dynamic engagement where agency, decision-making and being able to choose were important. However, one of the three participants did not want to choose and left the decision-making to the staff.

Kjerski, Nygard et al (2008) make three points relevant to the current research. Firstly, some patients' preference for a shared approach to decision-making seems important. Secondly, not all patients are prepared to exert their rights and accept responsibilities for decision-making. Thirdly, arising from the second point, patients also make decisions by themselves, for themselves and others, without the direct assistance of staff, such as the decision to not accept responsibility and exert rights.

However, the usefulness of decision-making models, for both staff and patients, is that they demonstrate an aspect of some of the different types of relationships in health care. Moving this argument forward, health care practitioners may prevent older people becoming involved in their rehabilitation through the imposition of particular decision-making models (Gadow, 1989). This is exemplified in the Eshun model of rehabilitation. Eshun (1999) discusses a model of rehabilitation based on a functional model of health using conceptualisations of the work of Henderson (1966) Orem (1980) and Wiedenbach (1964) as the theory bases. In this model, although the older person's needs are reported to be taken into account, perhaps demonstrating the use of the interpretive model of decision-making, the model is functionally-based, concerned with outcomes. Decisions about treatment are made according to standard scores developed from questions or performance criteria written by the health care staff and achieved by the patient. Experienced practitioners will be able to compare patients based on scores, using the model, in a normative way, ignoring the social base of rehabilitation.

The dominance of the functional approach to rehabilitation in the Eshun model of rehabilitation (Eshun, 1999) might demonstrate a paternalistic, informed choice or interpretivistic way of decision-making which arguably signposts the dominance of the practitioners’ way of working in health care practice. This “way” does not significantly incorporate the views and ideas of the patients in decision-making. Similarly, Ekdahl, Anderson et al. (2010) reported that the participation of frail elderly patients, in medical decision-making, is primarily a question of good communication and information and not participation in decisions about medical treatments. This indicates an interpretive or informed choice approach to decision-making which does not take into account how patients may wish to make decisions.

Comparing the current research with the different types of research described above, the meaning of involvement, for older people in their rehabilitation after acute illness, can be classified as socially-based and concerned with the patient practitioner interaction within the social process of rehabilitation. Therefore, in this review of the rehabilitation literature socially-based, research that considers the interaction between the patient and the staff is considered most useful.

Locating the Literature and Search Strategy

CINAHL and Medline are useful databases for this literature review because they incorporate the professional literature from those Professions Allied to Medicine concerned with older people's rehabilitation, physiotherapy, occupational therapy, nursing and social work. A literature search using CINAHL and Medline databases and combinations of the terms "rehabilitation" AND "older pe*" OR "elderly" AND "involvement" OR "engagement" OR "participation" in the abstract, retrieved over 2000 peer reviewed research papers from between January 1990 and September 2012. The term "older pe" was used as an inclusive term to capture terms such as "older person," "older persons" and "older people". Using the classification system discussed above, the research was separated into functionally-based and socially-based literature. Within the socially-based group, the literature was separated into that concerned with outcomes and that concerned with the interaction between patients and health care staff.

Functionally-Based Research Approaches to Rehabilitation

Much of the functionally-based research has a realist basis and is concerned with measurable improvements within specific time periods. Cameron (2010) discusses rehabilitation in this way describing models of rehabilitation in terms of those which have been tested for their efficacy at achieving improvements of function. Examples of other research of this type, include ways of maximising functional rehabilitation, for example, (Harris et al., 2010) and predicting outcomes of rehabilitation based on functional improvement (Denkinger et al., 2010).

Wade and de Jong,(2000) also discuss rehabilitation in a functional way as

> “A reiterative, active, educational problem-solving process focussed on a patient’s behaviour (disability) with the following components: assessment, goal setting, intervention and evaluation” (p 1386).

This definition is based around a functional model of health because it is concerned with procedures, assessment, goal-setting, interventions and evaluation. It is not concerned with the conceptualisation of the meaning of changes in function within a relationship between those who deliver care and treatment and the older people receiving rehabilitation. In this way the outcome is more important than the process which led to the outcome. Research using this approach underplays the relationships with patients and, though useful, does not easily help in the development of a deeper, conceptual understanding of the older person’s involvement.

In their consideration of the evidence of systematic reviews, Sinclair and Dickenson (1998) proposed a wider definition of rehabilitation that made it clear that rehabilitation was concerned with patients’ needs as defined by them.

> “A process aiming to restore personal autonomy to those aspects of daily life considered most relevant by patients or service users and their family carers” (p1).

This definition still adopts a functional approach but does demonstrate an understanding that the direction of rehabilitation should take into account the service user and their family and, implicitly, incorporate some sort of user involvement into rehabilitation design. Research of this type seems to use a narrow definition of personal autonomy, based around functional restoration.

A deeper understanding of personal autonomy might have included, for example, patient choice, arising from more shared decision-making, patient preferences and an inclusion of previous experiences of the patient. Practice based on the Sinclair and Dickenson (1998) definition of rehabilitation is therefore more likely to be of practical and functional value and does not concern itself with the processes within relationships. The emphasis on the practical and functional values underplays the importance of the on-going relationship between the health care practitioners and their patients.

Attempts have been made to measure user involvement (Storm et al., 2010) and suggest that practitioners' knowledge of body function can promote recovery (Jang, 2010). However, these tools do not include a measurement of the type of relationship between older people and their practitioners in rehabilitation and so are of functional design. In this way, quantifiable measures of involvement use a similar approach to functional models of health. In symbolic interactionist terms, (Blumer, 1969), tools that aim to measure social constructs, such as patient involvement, rely on reified qualitative terms by which involvement is categorised. Use of these tools will produce a score and therefore a result. Superficially, this type of research may also seem to measure the relationships in rehabilitation. However, the tools used to measure involvement in rehabilitation must be able to define involvement in such a way as to encompass the values of the person in rehabilitation at that time, which includes the type of relationship within which the rehabilitation is delivered. Single research tools and methods are unlikely to have this spread within them and so decisions based on information from measurements of involvement are unlikely to be shared in terms of the patients' values.

Socially-Based Research Approaches to Rehabilitation

This section demonstrates that although patient involvement in rehabilitation is an espoused goal, for many this is not achieved.

The social basis of rehabilitation is concerned with the relationship between the patient and the staff. On the patients' side of the relationship, when entering the rehabilitation unit, the older person is likely to be physically weak and cognitively naive about the resources that might be used to help him or her. The older person may not be able to join in the health care discourses competently, because of lack of familiarity with the vocabulary used and because the older person is at the beginning of a relationship with health care practitioners. Conversely, the health care staff, as a pre-formed group, may demonstrate longstanding stable, professionally-based relationships and may be distant from their patients. On the staff side of the relationship, although many practitioners believe they involve their patients in, for example, goal setting providing hope for the future (Bays, 2001), there is evidence that this is difficult and is influenced by social constraints such as time and prioritisation of workloads (Parry, 2004, Schulman-Green et al., 2006). The reasons for this are varied. Some staff may be insensitive to the patients' wish to participate (Lund et al., 2001, Florin et al., 2006, Tutton, 2005, Florin et al., 2008) whilst others may not be able to relate physiotherapy, occupational therapy or nursing tasks to the personal goals of the patient (Lequerica et al., 2009, Vik et al., 2009, Deck et al., 2009, Gibbon and Kenney, 1993). Overall involvement of patients in their rehabilitation is thought to be able to be improved markedly (Daremo and Haglund, 2008, Andersson et al., 2009, Almborg et al., 2009).

It is into this social complexity that older people move within the context of rehabilitation, at a time when they need help with their physical, functional and social health equating to ICFDH Levels One to Three (World Health Organisation, 2001). Part of this help is managed through the provision of information (McKain et al., 2005). McKain et al (2005) undertook a thematic analysis of interviews with nine patients, interviewed soon after admission to a rehabilitation unit, enquiring about the information patients received at this stage of their rehabilitation. The themes that emerged suggested that rehabilitation was seen as a “ticket out [of care]” (page 704) and that rehabilitation was “a good thing” (p704). Three other themes, ”Doesn’t matter if I don’t know”, “I will adjust in my own time” and “Information was not always useful (p708), suggest that; the quality of the information was suspect, the information provided was not always useful and that the patient was not always ready to receive the information. This notion of the provision of timely information is supported by two further studies. The first study (May et al., 2006) produced two main themes: information access and the need to know, which were influenced by learning readiness, emotional readiness, how, and the way problem exploration was carried out and the way the family was involved. The second study (Kåringen et al., 2011) concluded that the practitioners role was to ensure information was given when the person was ready to receive it and the patients role was to act on their obligation to achieve their goals.

Research that Identifies the Value of Relationships between Patients and Health Care Staff.

This section demonstrates the dichotomy between research that reports the need for involvement but underplays patient preferences and research that is concerned directly with the patient experience.

Some of the research that recognises the value of relationships between patients and health care workers has suggested that it is the role of the health care staff to involve patients in their care, for example, (Takahashi et al., 2005, Tripicchio et al., 2009). Additionally, it has been demonstrated that user involvement can be increased through practice development based on user experiences (Dewing et al., 2006). However, this type of research is of limited relevance to this current study because its central focus is the development of practice and it therefore under plays the important role the patient may play in his, or her, rehabilitation.

Other practice-based literature espouses the virtues of involvement and participation without defining these terms. For example, Peterson, Hounsgaard et al (2008) and Daremo and Haglund (2008) suggest that user participation and involvement have a positive effect on the rehabilitation process and outcome in mental health, but they do not attempt a definition of involvement. Similarly,Olsson et al (2007) suggest that engagement is important in rehabilitation after hip fracture (discussed in more detail later in this chapter) and Nilsson and Nygård (2003) suggest that good relationships activate patients engaged in rehabilitation activities operating through reflection and transformation. However, by not considering the nature of involvement, or engagement these authors use the terms without a definition a conceptualisation of the important role involvement plays in the relationships staff have with patients and patients have in social groups.

The basis of the relationship between patients and staff cannot be ignored if a relationship that is useful to the older person is to ensue (Armstrong and Mitchell, 2008). For example, Daremo and Haglund (2008) used a questionnaire design with a total sampling (n=115) technique. The patients who completed the questionnaire did not help to devise it, so the subjects and wording of the questions came from the perspective of the researchers alone. The second part of the research provided richer data through interviews (n=10) and found that

> “Important factors related to activity and participation were: agreement concerning the treatment plan, discussions about expectations, creating conditions for engagement in activities and providing patients with opportunities to take responsibility” (p131).

However, there was no attempt to investigate, for example, what was meant by “conditions for engagement” or “opportunities to take responsibility”.

Hammel et al (2008) using focus groups with 63 older people, reported that participation was conceptualised as a cluster of values including active and meaningful engagement. Supporting this finding, Mangset et al (2008) identified some factors that might enhance meaningful engagement from a sample of 12 patients during and after rehabilitation following stroke. The participants perceived that

> “To be treated with respect and dignity” (p825)

was a core factor contributing to their satisfaction with the rehabilitation services. This main factor was divided into five subcategories: (1) Being treated with humanity, (2) Being acknowledged as individuals, (3) Having their autonomy respected, (4) Having confidence and trust in professionals, and (5) Dialogue and exchange of information.

These practice-based findings indicate how the person in rehabilitation wants to be acknowledged as they act in their daily lives (Vik et al., 2008). Additionally, people in rehabilitation want to have their experiences, as expressed by themselves, taken into account by practitioners (Wottrich et al., 2004). These findings suggest that a functional definition of the success of rehabilitation alone does not incorporate a holistic view of the process of rehabilitation. The perception that the attitudes of older people towards social engagement may have a greater influence on their rehabilitation status than health care interventions (Entwistle and Watt, 2006, Lilja et al., 2003, Burton, 2000), is important in this current research.

Research that Recognises the Need to Identify and Understand Patient Value Sets during Rehabilitation

This section identifies the socially-based rehabilitation literature that is concerned with a recognition that patients have something of themselves to offer in therapeutic relationships.

In a study describing the incentives and disincentives to join in an exercise training program using telephone interviews and sampling 209 older people, Schneider et al (2003) recognised the need for nurses who worked with older adults to take into account the

> “Lifestyle, age specific obligations and set of values affecting this cohort’s participation” (p21).

However, this recognition is superficial. Within this group of 209 older people the set of values may have been much wider than that categorised on an age-related basis only. This superficial consideration of values was also reported by Schulman-Green et al (2006) who concluded that goal setting, in terms of patient preferences, was not given the priority it deserved because of time limitations, presumptions about the similarity of patients’ goals, a focus on symptoms and disinterest.

Tutton (2003) berates the notion of practitioner-led goal setting recognising the need to know the individual through partnership. Tutton’s (2003) research used three focus groups and 24 staff and 19 patient interviews, to consider how patients were involved in their care. Tutton (2003) concluded that practitioners working with older people, should develop a deeper understanding of participation, defined as

> “A dynamic process... enacted through the themes of facilitation, partnership, understanding the person and emotional work” (p143).

However, the role the patient should play in this dynamic process is unclear.

Other researchers have considered how patients are involved and have categorised patients into groups. For example, the research of Kidd et al (2009) with colorectal cancer patients, divided the research group into perceived controllers, who viewed their active involvement in their self-care positively and low controllers, who thought less positively of their need to be involved in their self-care and were more likely to think that this was the responsibility of others. This type of socially-based research is important to this current research as it provides useful information about how older people might react to their rehabilitation. However, the significance of these findings is weakened in this longitudinal study, of only 11participants, as the participants were only sampled twice, once before and once after treatment. Additionally, the staff in the colorectal unit did not take part in the research as participants. Interviewing the practitioners may have added another dimension to the research, supporting or altering the final results. Finally, the nature of perceived control and how this was used by the older people in their treatment with the staff, was not discussed, making the research less useful in developing an understanding of the value-sets of the patients and practitioners. This is important as it would be useful to know how the different groups of patients were managed by the health care staff, the nature of their relationships, and what this meant for their treatment outcomes.

Olsson et al (2007) also categorised their research participants, into three categories. The first of these were the “Autonomous”, who were self-sufficient, used to taking care of themselves and who searched for relevant information. The second group were the “Modest” frail patients in need of more support who wanted information, but did not ask for it. The third group were the “Heedless”, patients who were already dependent, were not aware of their own responsibilities and not interested in information. This research seems to expand the categories discussed by Kidd et al (2009), introducing a group of participants who were unable to act for themselves. However, the relationship between the two studies is hampered by the use of different vocabulary. Additionally, the authors do not discuss the meaning of involvement within the relationships with the practitioners except that, within the discussion of this work, walking after a fall and hip fracture seemed to trigger a “Zest for life” (p857). This finding of improvement leading to an apparent increase of involvement with “life” may be a function of the sampling procedure or the sample size. It would be interesting if a “Zest for life” occurred in every case in rehabilitation after hip fracture. The research of Olsson, Nystrom et al .(2007) would be of even more use to this current research, if the reasons for the “Zest for life” had been explored more thoroughly.

This “Zest for life” might be concerned with increased motivation. It has been reported that a lack of motivation contributes to a lack of participation (Gori et al., 1984). This notion is supported by a study of older people who had sustained a hip fracture, received rehabilitation one year previously, and who recognised the importance of motivation retrospectively (Young and Resnick, 2009). Additionally, Young and Resnick (2009) reported that self-determination, along with a positive attitude, social support and full engagement in recommended rehabilitation activities, played significant roles in making rehabilitation work. This is discussed in relation to the research constructions in chapter 12 (Study Discussion). Other researchers have suggested that the data about preferences of control and comfort are not categorical but continuous, as patients express a wide variety of values and beliefs about involvement in decisions in end of life care (Volker et al., 2004). However, none of this research discusses how these roles, values and beliefs were managed in rehabilitation.

Other socially-based research studies have recognised the importance of social interactions and suggested the need for a partnership relationship between nurses and their patients (Cline et al., 2011, Read and Maslin-Prothero, 2011, Penney and Wellard, 2007, Eldh et al., 2006, Sahlsten et al., 2009, Hoglund et al., 2010) and a sense of engagement, alliance or affinity with the system (Staniszewska and Henderson, 2005, Staniszewska and Ahmed, 2000, Natterlund and Ahlstrom, 1999, Hall et al., 2010). All of these papers discuss the benefits of involvement of patients to functional outcomes without discussing patients' perspectives. This is a feature of a considerable amount of rehabilitation research (Eldh et al., 2006) which reduces the usefulness to this current research through an apparent failure to recognise the need to understand value-sets from the perspective of both staff and patients.

A systematic literature review by Hall et al., (2010) summarises this type of socially-based research suggesting a need for a partnership between practitioners and their patients. In their review of six databases, searching for prospective studies of patients undergoing physical rehabilitation, it was reported that the working alliance between older people and their therapist is positively associated with

> “ (1) Treatment adherence in patients with brain injury and patients with multiple pathologies seeking physical therapy, (2) Reduction of depressive symptoms in patients with cardiac conditions and those with brain injury, (3) Treatment satisfaction in patients with musculoskeletal conditions, and (4) Physical function in geriatric patients and those with chronic low back pain” (p1099).

However, the nature of these positive associations was not researched, which was recognised as a limitation within the reviewed literature. Although the review begins to associate patients’ relationship with health practitioners and positive functional outcomes, it does not identify the nature of the working alliance. This research, in line with the other research, does not address the conceptualisation of the value-sets demonstrated by the health care staff and the patients within a therapeutic working alliance.

Research that Demonstrates the Values in Relationships that Patients bring to Rehabilitation

This section identifies research literature concerned with health care relationships. Some of the socially-based rehabilitation research does discuss the values that patients bring to the health care relationship. This helps to locate the current research, facilitating an understanding of the nature of some of the concepts demonstrated within health care practice. Overall, this research suggests that a person-centred approach to rehabilitation may assist in enhancing patient involvement and motivation towards rehabilitation, for example, (Harris and Eng, 2004, Murphy and Lam, 2002, Pryor and Buzio, Van de Velde et al., 2010, Gillespie et al., 2004, Andrews et al., 2004, Lyttle and Ryan, 2010, Delmar et al., 2009). Van de Velde et al's (2010) grounded theory approach to conceptualising participation in 11 people with spinal cord injury in rehabilitation exemplifies this research. The authors identified three different categories of participation: social participation, occupational participation and socio-occupational participation. Within these the category "participation" was conceptualized as a set of values which included

> "Experiencing free choice to perform activities, performing according to the person's identity, experiencing personal growth, belonging by experiencing trust and security, feeling validated, having a sense of control, experiencing a sense of importance and finding equal identities"(p346).

These results are heavily weighted towards the social basis of rehabilitation and are concerned with the intrinsic nature of values and beliefs. In the conclusion of the paper the relationship between activities performed and social interactions is well made

> "From a client perspective, participation is a complex, multidimensional construct and can be considered as a dyad between the individual's social interactions and the specific activities performed" (p355).

Failure to recognise this dyad has been reported by Lui and MacKenzie (1999) who, with a purposive sample of 15 Chinese older people in post-acute rehabilitation, demonstrated the participants' need for information. More importantly in terms of this current research, Lui and MacKenzie (1999) reported the need for the participants to be recognised as persons within a relationship where physical and psychological needs were seen as of equal importance. A failure to recognise patients as persons may not create useful relationships based on mutual informing and negotiation (Jewell, 1994).

This idea of person recognition is taken further in Delmar et al's (2009) phenomenological research on older people's experience after total hip replacement. Delmar et al (2009) interviewed six people who were working on rehabilitation exercises at home and concluded that nurses should not focus only on patient participation within goal setting, but rather try to integrate personal life experiences into rehabilitation. By integrating personal life experiences into the experience of rehabilitation, it was asserted that rehabilitation becomes part of the older person's life rather than a separate entity.

The notion that taking account of the person and their personhood within social interactions during rehabilitation is important is also supported by Hawley (2009) who used grounded theory to explore what might encourage nine participants over 60 years old to exercise at home after a fall. Hawley (2009) found that determination to gain independence and the availability of social networks impacted on the uptake and continuance of exercise. Hawley's (2009) research suggests that the desire for independence and social interaction are key to participation in useful rehabilitative practices, which in turn has been found to improve rehabilitation outcomes (Lenze et al., 2004b). Hawley's (2009) research is discussed in terms of the research constructions in chapter 12 (study discussion).

The values that people bring with them to rehabilitation, for example determination and the social interactions that are demonstrated during rehabilitation, discussed above, have been characterised in the terms Perceived Controllers and Non-Controllers (Kidd et al., 2009) and the Self-Sufficient, Modest and Heedless (Olsson et al., 2007) discussed earlier. Patients also bring with them a wider variety of personal stances and values which may depend on their demographic status such as gender, education level and home living conditions (Florin et al., 2008) that they use in the relationships they develop in the rehabilitation unit.

The values that people bring to their rehabilitation are assessed through direct social interaction (Benbassat et al., 1998) and Eldh et al (2008) has shed some light on this social interaction eliciting the values of patients. Eldh (2008) found that patients felt they did not relate well to the health care staff. Within this, the patients reported a lack of enough and appropriate information, a lack of personal recognition and feelings of insecurity within health care interactions. This is complemented by research that demonstrates how nurses viewed older patients as being both passive and reluctant to participate in decision making (Jewell, 1996). This socially-based research points to a need for greater understanding of value sets that patients bring to health care, so that they can be taken into account to enable health care practitioners to support and sustain people’s involvement (Kidd et al., 2009).

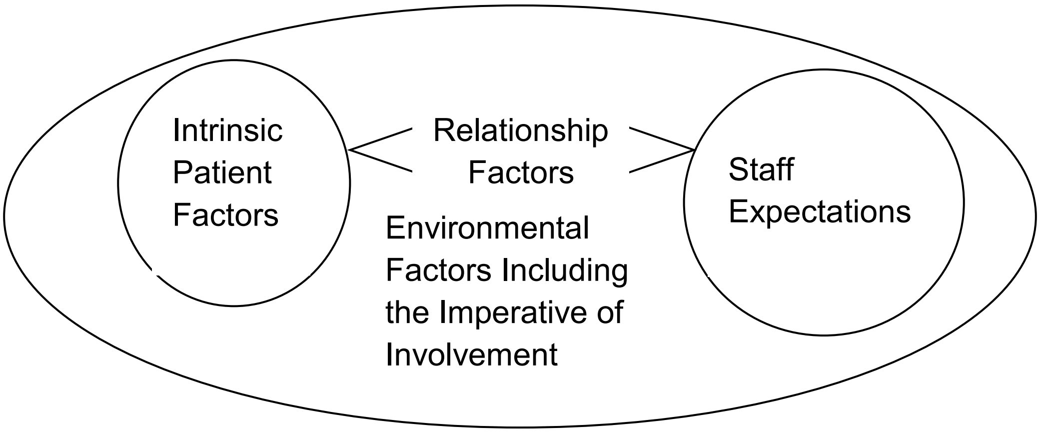
Considering the level of involvement more widely in their review of the literature between 1997 and 2007, Lyttle and Ryan (2010) identified factors influencing older person’s participation in care. Lyttle and Ryan (2010) found seven key themes: the concept of participation, the need for older people to be involved, autonomy and empowerment, patients' expectations, benefits of participation, factors influencing participation and precursors to participation. Lyttle and Ryan (2010) noted that participation should not be achieved at the expense of patient autonomy and choice.

These seven factors can be put into three groups.

1. **Environmental factors including the imperative of involvement** (factors influencing participation, precursors to participation, the concept of participation, the need for older people to be involved and the benefits of participation).
2. **Intrinsic Patient factors** (patient expectations).
3. **Relationship factors** (autonomy and impairment and precursors to participation).

Grouping the factors in this way enables other factors, which may be important, to be identified, such as health care staff expectations. Put into diagrammatic form (Figure 3.1) it can be seen that involvement seems to be concerned with the relationship between the major actors and the social environment.

Figure 3.1 Aspects of Patient Involvement in their Care and Rehabilitation (Adapted from: Lyttle and Ryan, 2010)



The conclusions of this type of research suggest that there is a need to explore the nature of the dyad between the social interactions and functional improvement. Expanded, the social interactions are those that go on between the patients, staff, friends and family related to the activities performed in context. This is now discussed in terms of the move away from more traditional, paternalistic care towards person-centred care.

Developments toward Person-centred care

The above literature review suggests that the key to understanding the nature of patient involvement in their rehabilitation (Figure 3.1) is concerned with the relationships between the health care staff and the person in rehabilitation, focussing on the social environment and, in the case of this current research, the context of rehabilitation. One approach to care, which differs from the traditionally paternalistic approach, discussed in Chapter Two (Background) is care centred on the needs of the patient.

A definition of patient-centred care has been reported to be elusive (Gzil et al., 2007, Nolan et al., 2004, Epstein et al., 2010). However, there have been attempts to characterise desired behaviours and understandings that demonstrate patient-centred care, for example the Institute of Medicine,(Institute of Medicine, 2001) suggested that patient-centred care is care

> “That is respectful of and responsive to individual patient preferences needs and values and ensuring that patient values guide all clinical decisions” (p6).

More recently Drach-Zahavy (2009) expanded this stating that patient-centred care

> “includes enacting such behaviours as exploring the social and psychological (as well as the biomedical) aspects of the patient’s health status; understanding the personal meaning of the illness for the patient by eliciting their concerns ideas, expectations, needs, feelings and functioning; promoting the understanding of the patient within their unique psycho-social context, sharing power and responsibility and developing common therapeutic goals that are concordant with the patient’s values” (p1465).

These definitions move the focus of health care decisions away from paternalism, taking account of the patient preferences and values in the area of health care. However, these definitions also demonstrate that patient-centred care limits the centredness in care by focussing on specific health care attributes of the person (McCance et al., 2011) where people are seen as patients first and a person second (Parkinson, 2004). This focus on specific attributes also occurs in terms used that are similar to patient-centred care such as client-centred care (Wressle et al., 2002).

Person-centred care is a different conceptualisation of care which, though related to patient-centred care, has a broader philosophical base incorporating personhood (Røsvik et al., 2011) rather than patienthood. The origins of person-centred care are generally agreed to be within the UK (Dewing, 2004) based humanistic psychology (McCance et al., 2011) and first applied to people with dementia (Kitwood, 1997, Dewing, 2008).

Kitwood,(1997) defined personhood in a sense not concerned with the needs of a patient but as a standing or status

> “A standing or status that is bestowed upon one human being by others in the context of relationship and social being. It implies recognition, respect and trust” (p8).

McCormack (2004) analysed Kitwood’s (1997) conceptual definition into four concepts: Being in relation, Being in place, Being in a social world and Being with self, in line with the hermeneutic phenomenological tradition of *Dasein*. Used as a foundation for person-centred care, this explanation of personhood recognises the older person in rehabilitation as a person in the present, in context and includes their lived life experiences and relationships, (Parkinson, 2004) much of which is independent of the health care system. The acceptance of a person in this manner does not require specific attributes, as patient-centred care does, other than being a person, a human being (Kontos, 2005, McCormack and McCance, 2010). Considering a person in this holistic way is a precursor to the development of a closer relationship within care which facilitates care that goes beyond functional benefit within trusting explorative relationships (Price, 2006) .

In a similar way to patient-centred care, person-centred care has been characterised in terms of desired behaviours and understandings as

> An approach to practice established through the formation and fostering of therapeutic relationships between all care providers…patients and others significant to them [in their lives] (p1). (McCormack et al., 2011)
> “It [Person-Centred Care] is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” (p13) (McCormack et al., 2010a).

Person- centred care requires

> “…a continuation of self and normality” (Edvardsson et al., 2010a) (p2614).

The difference between person-centred care and patient-centred care is therefore, that person-centred care has a broader orientation than patient-centred care which signals the need for a more open approach to the person . This approach is based in interaction and a specific ethical stance which prioritises the quality of therapeutic relationships (Edvardsson et al., 2010a). The inclusion of the whole person embodied within the meaning of person-centred care means that person-centred care incorporates other terms such as patient-centred care.

It has been reported that person-centred care, is “multidimensional” based on people’s subjective experience of illness (Brooker, 2004, Brooker, 2007, McCormack, 2004, Edvardsson et al., 2008). However, based on the above understandings, person-centred care has, potentially, an infinite number of dimensions relating to the unique encounters between health care staff and their patients. This understanding means that the current research is more closely associated with person-centred care than patient-centred care.

Relationship-centred care

Practice research about relationships in health care seems to be increasing. Examples of practice interest into relationship-centred care include, Smith, et al (2010), Andrews (2009), Partis (2009) and Sidani (2008). Relationship-centred care is a term closely associated with person-centred care. However, the nature of this association is quite different from the association with patient-centred care, described above. The association between person-centred care and relationship-centred care occurs because like person-centred care, relationship-centred care has a broader focus than the attributes of specific groups such as patients. This broader focus includes how the person interacts with those around them (McCance et al., 2011). It has been argued that relationship-centred care, which emphasises the relationships between patients in their environment, as well as relationships between patients and staff, is a more useful term and conception than person-centred care as it focuses on the interactions between all the parties involved in care (Nolan et al., 2001, Nolan et al., 2004, Tresolini and The Pew-Fetzer Task Force, 1994). It is further argued that relationship-centred care adds a different dimension to the concept of person-centred care characterised in the six conditions of the senses framework which are required to be experienced for good care to be the result (Nolan et al., 2008). These conditions are: a sense of security, a sense of continuity, a sense of belonging, a sense of purpose, a sense of achievement and a sense of significance. The senses framework forces an examination of these relationships because all the people in the relationship, including the staff, are meant to meet the six conditions (Nolan et al., 2006). This notion of relationship-centred care has been used to explain the success of a community dementia support service which provides support to carers of people with dementia (Ryan et al., 2008). Within this community dementia support service the senses framework (Nolan et al., 2008) was thought to promote

> "…a more inclusive vision of dementia practice and research" [than person-centred care] (p79).

as described by Nolan et al (2002). Additionally the senses framework was thought to unite carers, those with dementia and staff so that the quality of life of all groups are altered in the care partnership (Ryan et al., 2008). This unification is thought to be able to be translated into patient and practitioner behaviours, resulting in different health care outcomes (Tresolini and The Pew-Fetzer Task Force, 1994).

This more inclusive vision within relationship-centred care is also concerned with a move away from a focus on individuals and their quality of life, thought to be conceptualised by person-centred care, and so captures a person's interdependencies and reciprocities that underpin caring relationships more fully (Nolan et al., 2002). However, the conceptualisation of person-centred care is holistic and includes "Being in relation" (McCance et al., 2011, McCormack and McCance, 2010) and therefore includes

> "…all those involved in a caring interaction and therefore encompasses patients, clients, families, carers, nursing colleagues and other members of the multidisciplinary team" (p4).

These arguments further demonstrate the complexity of the conceptualisation of person-centred care in its fullest sense and express some of the challenges of implementation of the concepts. The emphasis placed on care in a particular context is likely to depend on the specific care situation. For example, where relationships are required to be emphasised as in the Ryan et al (2008) study discussed above "Being in relation" may need to come to the fore in the operationalization of person-centred care. Where care is required to help a person understand his medication as part of his need to stay at home alone, rather than move into an institutional environment, "Being with self" may be more important for a time. This does not mean that the other concepts within person-centred care: Being in relation, Being in the social world and Being in place, are neglected. This argument suggests that relationship-centred care, just like patient-centred care, as discussed earlier, is included within person-centred care.

Using the search terms "person-centred care" in the title or abstract of the CINAHL database between 1994 and October 2012 produced 135 peer reviewed research papers of which 17 had "older people" in the title or abstract. However, only one of these research papers was about rehabilitation. Considering the 17 papers with older people and person-centred care in the title or abstract, six were concerned with older people and cognitive impairment, three were concerned with staff views, one with mental health issues, one with the use of bedrails, one with dignity, one with government policy and one with rehabilitation (Benten and Spalding, 2008).

Benton and Spalding's (2008) phenomenological study explored service users opinions of rehabilitation within an intermediate care service and found that the care delivered, in terms of assessment and goal setting, interventions and transfer home, did not deliver person-centred care. This finding is not surprising as the research literature concerning older people and person-centred care is replete with examples of the challenges of implementing person-centred care from different perspectives (Merrell et al., 2012, Thompson, 2011, Tucker et al., 2009, Hughes, 2008, Schofield, 2008, Woolhead et al., 2004, Lynch et al., 2011, Mullay et al., 2011, McCormack et al., 2011, Bolster and Manias, 2010).

There are examples of models that have been developed to audit and assist in the implementation of person-centred care, for example the Person-Centred Nursing Framework (McCormack and McCance, 2010), the VIPS Framework (Røsvik et al., 2011), the Recovery model (Gavan, 2011), the Person-Centred Care Assessment tool (Edvardsson et al., 2010b) and the Older Person Acute Care (OPAC) model (Peek et al., 2007). However, the empirical bases of some of these models and frameworks have been reported to be unclear (Edvardsson et al., 2010a).

The existence of the various models, frameworks and assessment tools, together with the challenges in their operation, suggest that the implementation of person-centred care is complex and that a complete understanding of the concepts not established by health care practitioners. However, consistent across the frameworks, models, tools and person-centred care practice is an understanding that: person-centred care exists within a therapeutic relationship with the person and those significant to them; there is an acknowledgement that the person is unique and care is based around the patient's beliefs and values within a care partnership (McCance et al., 2011, Bolster and Manias, 2010, Hughes et al., 2008).

It is this care partnership or therapeutic relationship that the current research explores in the investigation into the meaning of involvement for older people in their rehabilitation after acute illness.

Conclusion

The current research is located within socially-based rehabilitation research, concerned with the intrinsic values within relationships between patients and health care staff. This type of research is seen most clearly within person-centred care. Although the nature of relationships is a key part of person-centred care the meaning of involvement within these relationships has not been researched.

Opie (1992) suggested that without a shared understanding of involvement, work, an older person/practitioner partnership may obscure, for example, power differentials and fail to develop involvement beyond a superficial level. A lack of understanding of the meaning of involvement is, therefore, a gap in the socially-based rehabilitation research literature and is worthy of investigation prior to understanding cultural conventions and power differentials. This gap is reduced by the current research which informs the patient involvement debate in the area of direct care and the socially-based rehabilitation research literature.

Part Two

Chapter Four: Theoretical Framework and Method

Introduction

This chapter moves the imperative to increase the understanding of the meaning of involvement forward, through a discussion of the theoretical foundations of the current research and the method used. The chapter moves through a systematic discussion of the ontology, epistemology and methodology, which explores and explains the choice of research perspectives. Within these theoretical foundations, congruent with the chosen ontology and epistemology of relativism and constructivism respectively, the chapter discusses the social scientific influences on the research. These influences include the work of Mead (1962) in pragmatism, Bulmer (1969) in symbolic interactionism Heidegger (1962) and Gamer (1975) in interpretation, and Glaser and Strauss (1967) and Charkas (2006) in grounded theory. Examples from this current, and other research, are used to illustrate interpretations.

Theoretical framework

The philosophical position of research informs the theoretical framework from which the research is built (Munhall and Oiler, 1986). The theoretical framework asks important questions about the ontology, epistemology and methodology of the research (Guba, 1990), all of which must be congruent with the methods chosen (Annells, 2006, Blumer, 1956). Together, these aspects of the theoretical framework form a conceptual paradigm, a world view, representing a particular set of propositions that explain perceptions used in the research (Sarantakos, 1993).

Ontology

The study of ontology is concerned with the form and nature of reality (Guba and Lincoln, 1985, Crotty, 1998, Guba, 1990). The theoretical framework discusses how reality is understood, for example, whether the philosophy chosen supports a belief in substance dualism or not. Conceptual paradigms that include substance dualism, such as realism and critical realism (Crotty, 1998, Krauss, 2005, Packard and Polifroni, 1990) and objectivism (Crotty, 1998, Bryman, 2008), separate mind and body. Discussions on this subject will use realism to represent ontologies that support substance dualism.

Reality can also be thought of as occurring in the mind with no substance dualism. This ontology is known as idealism (Packard and Polifroni, 1990) and in social science; relativism (Guba and Lincoln, 1994). The following discussion applies realism and relativism to the issue of researching the meaning of the term involvement

Realism

Within a realist ontology objects are seen to exist independently, having their own intrinsic meaning which everyone can share from an empirical perspective (Crotty, 1998). This stems from the inclusion of substance dualism. Within this paradigm, objects reside outside of human consciousness, have their own unconditional existence (Stedman-Jones, 1998) and are governed by universal physical laws which are not alterable by human effort (Guba, 1990). Since objects have their own empirical reality and are governed by universal laws, the scientific study of these objects is a search to describe and explain the objects, the relationships they have with other objects and the universal laws that govern them, as verifiable truths (Guba, 1990). Within realism, it is understood that knowledge will always be incomplete and that science moves towards the truth rather than discovering the truth (Guba, 1990). However, verification of research results is possible through demonstrations of the universality of the research results within given conditions at a particular time. This paradigm is useful when the research is concerned with empirical studies and tangible objects. Examples of this type of research include clinical trials (Trappes-Lomax et al., 2006) and fundamental natural science projects such as the discovery of the structure of DNA (Watson and Crick, 1953).

Relativism

When the objects to be researched are intangible, for example researching involvement, a realistic approach is more problematic. This is because concepts such as involvement cannot be seen from a universal perspective. Relativism is the proposition that there is no absolute truth or reality (Stedman-Jones, 1998) and that reality exists in the mind (Guba, 1990). Explaining reality based on a relativist ontology, the individual mind creates meaning based on perceptions of the object and meaning is dependent on human consciousness (Guba and Lincoln, 1994). In these circumstances truth is relative to the individual person's frame of reference, based on reflexion and interaction at a particular time (Denzin, 1970).

Social research is often characterised by being concerned with relativist meanings that individual people and groups attach to their relationships (Williams and May, 1996). Since within relativism objects do not have a universal meaning, scientific study sets out to develop understanding rather than to *discover* meaning. Verification of the scientific study is developed through the rigour of the study and by scientific acceptance of worthiness (Streubert and Carpenter, 1999).

An example of this type of study was the study of the informal roles of family care-givers in end-of-life care (Quinn et al., 2012). In this research, an ethnographic approach and participant observation, with semi-structured interviews of clinicians, patients and family members, was used to identify and develop the meaning of family member roles in intensive care units. This research demonstrated that family member roles, such as family spokesperson and patient expert, could not be discerned entirely by empirical study, but required an element of interpretation, guided by semi-structured interviews. This interpretation demonstrates relativist ontology (Annals, 2006a).

Epistemology

The difference in understanding of reality between the two ontological paradigms of realism and relativism informs and constrains the epistemology of the research. The epistemology is the study and justification of knowledge (Schwandt, 2001, Carter and Little, 2007) about how the research subject can be studied and how the subject can come to be known and understood (Guba, 1990).

If the world is viewed through a realist ontology then the epistemology used separates the researcher from the research and the researcher becomes an observer; this epistemology is objectivist (Guba, 1990). If the world is viewed through a relativist lens, an epistemology is required that facilitates better understanding through the creation of meanings that other people recognise as useful. These meanings may never be “seen” in an empirical sense and are constructed (a constructivist position) rather than discovered, using a subjectivist epistemology (Guba, 1990).

However, constructed meanings may be reified, to some extent, by consensus. When consensus occurs, although new meanings may not be verified by observation, they may still be accepted as true by many, in given circumstances at a particular time. There are many examples of this within qualitative research. In the research described above (Quinn et al., 2012), the authors invited others to agree to form a consensus about the roles of family care givers in an intensive care unit. Similarly, Allen (2000) invited others to agree an association between bad housing and psychologically-based illness. The acceptance that the research constructions were positive and not spurious relies on the rigour of the scientific procedures in the research and the acceptance by others.

Methodology

The methodology is a strategy for devising, articulating and evaluating the research method (Carter and Little, 2007, Crotty, 1998). Just as the ontology informs and constrains the epistemology, the methodology is informed and constrained by the epistemology. For example, using a realist ontology and an objectivist epistemology, the researcher who sets out to discover something, would use an experimental methodology, based on the senses (observation in its widest sense) (Guba, 1990). The researcher, separate from the research arena, would make deductions from what is already known and formulate hypotheses about what might be as an independent observer. The researcher would then carry out experiments to test the hypothesis working on the basis that that the world contains objects known and unknown. An example of this occurred when Jacob and Monod, two French scientists, deduced the structure of the human gene from the then current knowledge then set out to discover the gene through experiment (Jacob and Monod, 1961).

Within relativist ontology and a constructivist epistemology a researcher would use a methodology which facilitated a better understanding of phenomena, to build up an understanding of meaning in context. Within this type of methodology, vehicles, such as interviews and focus groups, are used to create opportunities for meaning to be articulated. This is coherent with the idea that objects are given meaning in the mind of the individual, rather than observed in empirical investigation. Within the relativist paradigm, the researcher is much more associated with the research, there being no substance dualism. Therefore, opinions of social constructs, expressed through vocal and behavioural gesture, not only describe social phenomena, as they would in the realist sense, they also determine the formation of opinion about the phenomena which become part of the construction (Bandura, 1997). An acceptance of this demonstrates that meaning, language and behavioural gestures are inextricably linked and are active in the development of the social world from which no researcher can be an independent witness. (Weber, 1949).

> “All knowledge of a cultural reality, as may be seen, is always knowledge from particular points of view” (Weber 1949 p72).

Theoretical Frameworks as Human Constructs

Although coherence between the aspects of the research philosophy and the resultant theory is important, theoretical frameworks are themselves human constructs (Guba, 1990). Human constructs are not discovered, and there is no independent witness of them. Theoretical Frameworks are created to facilitate various forms of description, interpretation, understanding and explanation to provide meaning and are not technical truths (Atkinson, 1995, Carter and Little, 2007). Racher and Robinson (2003) entreat researchers not to let the conventional philosophical underpinnings of research, (any scientific consensus)

> “Restrict and limit their exploration of possibilities and the creativity in their efforts to address the growing challenges that await nursing science research” (abstract).

The Location of the Current Research within a Relativist Ontology

The meaning of involvement does not exist in the external world as it does not consist of publically observable phenomena. The meaning of terms like involvement are mental entities and human constructs (Williams and May, 1996). Additionally, a premise of this current research is that the meaning of involvement can be described through vocal and behavioural gesture within social groups. Therefore the paradigm most suitable for the study of involvement is relativism.

If the meaning of involvement were studied through realism, accepting a substance dualism, the expectation would be that the meaning of involvement was somehow indirectly, or directly, observable. This would attempt a correlation between the subjective state of the research participants (the mind) and report these as a social reality (the body). This position undermines the possibility of wide ranging subjective opinion of the meaning of involvement, demanding consensus which is difficult to achieve with intangible objects (Bonner, 1994). For these reasons the realist paradigm is not appropriate for this research.

The Location of the Thesis within a Constructivist Epistemology

Accepting involvement is a human construct, possibly varying within context, there may only be a superficial understanding of involvement in the general population (Opie, 1992). Although involvement may be recognised *a priori*, there is no specific and recognised understanding of the meaning of involvement for older people in their rehabilitation after acute illness, as discussed in chapters two (Background) and three (Literature review).

This current research requires an approach that commences with this *a priori* assessment of involvement, within the context of the research, in such a way that the assessment can be discarded or developed through the research process. As the research progresses and relevant phenomena, created between the participants and the researcher are captured, a more sophisticated, *a posteriori* understanding of the meaning of involvement will be able to be advanced for the scrutiny of others.

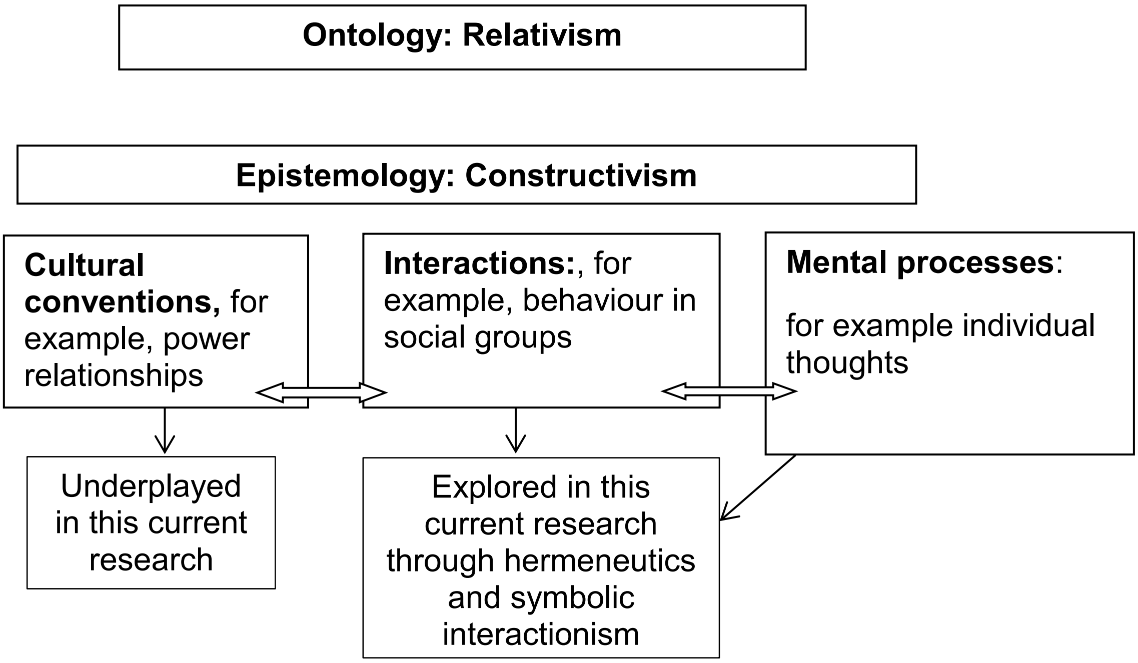
Locating this particular study of involvement within a relativist ontology informs and constrains the epistemological opportunities to develop this understanding. Guba and Lincoln (1994) discuss four epistemologies from which the research can be managed. These are positivism, post-positivism, critical theory and constructivism. Since post-positivism and positivism are not appropriate for the study of involvement having realism as an ontological basis, this research could be managed within the critical theory or constructivist epistemologies.

Critical Theory

Critical theory has been described as an ideological oriented enquiry (Guba, 1990) and is the examination and critique of society and culture concerned with transformation of social structure through an awakening from a false consciousness (Guba, 1990). That is, by understanding how society works, communities will be released from misunderstandings about how they live (Morrow and Brown, 1994). Critical theory is particularly concerned with issues of power domination and freedom (Guba, 1990). This current research, takes into account some aspects of the culture of the organisation, for example, the guidance for the assessment of older people suitable for admission to the Intermediate Care unit. This guidance is outlined in the service directory of the Intermediate Care unit, extracts of which are presented in Appendix One.

However, this current research concentrates on issues concerned with the interactions between the older people and the staff in an Intermediate Care unit, rather than the social structure of the Intermediate Care unit (Figure 4.1). The research intends to increase understanding in terms of “What is the meaning of involvement?” rather than “Why is the meaning so?” For these reasons the current research is more suited to the epistemology of constructivism (Schutt, 2009, Baker, 1992).

Figure 4.1 Three Interlinked and Inseparable Influences on the Location of this current Research within the Relativistic Ontology



Choosing constructivism as the epistemology pushes this current research towards other methodologies, such as those that consider mental processes and group interactions (Figure 4.1). Mental processes are the essences (Husserl, 1970) and interpretations (Gadamer, 1975, Heidegger, 1962) that reside in the consciousness of the individual. These essences and interpretations of the world form the basis of actions and interactions that can be accessed, in research terms, through language-based approaches where the researcher wishes to find out, for example, experiences of individuals (Bryman, 2008).

Linked closely to mental processes are the interactions that people have in their daily lives (Figure 4.1). These interactions facilitate the development of ideas about the world providing opportunities to change behaviour. These interactions can also be accessed through language-based approaches.

Constructivism

In this context, constructivism refers to the on-going study of human constructs and the meanings humans give to their experiences within a social setting (Charmaz, 2006, Guba and Lincoln, 1989). Researchers working within constructivism, seek to increase the understanding of objects, by finding ways of facilitating the expression of meaning held in the form of social constructions by the research participants (Guba and Lincoln, 1989). Meanings are modified by the participants' prior experiences and the interactions during the research. Analyses of these interactions about, for example, involvement, can be used to facilitate a construction of new and deeper meanings within the specific context (Denzin, 1970). The aim of research within constructivism is to develop a sophisticated, consensually-based understanding of phenomena in a particular social environment at a particular time (Schwandt, 1994).

The Choice of Methodology within Constructivism

The approach chosen for this current research emphasises the capture of meaning through interactions and is managed through symbolic interactionism, which has its roots in pragmatism.

Pragmatism

Gordon Herbert Mead studied and commented on social change as an evolutionary movement (Mead 1934). Mead discussed the tools of this social evolutionary movement in terms of communication as gesture, and language as a form of symbolic representation of the objects of the world (Mead, 1962).

> "The minimal society must be composed of biologic individuals participating in a social act and using the early stages of each other's actions as gestures, that is, as guides to the completion of the act. In the conversation of gestures of the dog fight, each dog determines his behaviour in terms of what the other dog is beginning to do.... Such an action is a type of communication; in one sense the gestures are symbols since they indicate, stand for and cause action appropriate to the later stages of the act..." (Mead, 1962) p *xx* (Introduction by Morriss, CW).

These objects include the tangible, such as desk, and the intangible, such as involvement, love and fear. Language, considered as a set of vocal gestures, can convey many ideas which, within a group, develop to form complex, collective understandings through the exchange and accumulation of experiences and shared meanings. In these terms, the social evolution of meaning is associated with an infinite, reflexive, contextual and interactional relationship with self and others through vocal and behavioural gestures. For example, social evolution is taking place in the United Kingdom with regards to how people regard their health and how help is asked for and received, as discussed in chapter two (Background).

The interactional, reflexive and contextual nature of social evolution ensures that it will always be incomplete. This situation can be exemplified locally when an older person commences rehabilitation. At first, the older person is unlikely to know exactly what will happen to him. To some extent he will react to the practitioners and his behaviour will be affected by the way he is treated. The older person will learn from the behaviour, the gestures of the practitioners, and act in new ways. Similarly, the practitioner has the opportunity to learn from the older person and act differently. In a partnership, both the practitioner and the older person have the opportunity to learn, act reflexively and socially evolve.

According to Mead, (1962) for gestures within social evolution to be significant, they must be understood in the same way as the communicator, that is, have the same meaning for the other person, the object, as it does for the speaker. In an older person-practitioner partnership, the older person and practitioner will have to come to terms with the language and behaviours that each uses. Additionally, because the older person is the partner that has come to be helped, the pressure might be on him, or her, to learn the language and accept the behaviour of the practitioners.

In these ways an equal partnership between older person and practitioner is difficult to achieve as discussed in chapter two, background. A more equal partnership may be facilitated, by an alteration of the practitioner’s vocal and behavioural gestures so that they actively take into account, and use, the language and behaviours of the older person to benefit collaboration. This will require some knowledge of the older person. However, the partnership is unlikely to be equal if the older person is passive and expects to be a receiver of rehabilitation, without thoughtful, reflexive action.

This reflexive facility within the tenets of pragmatism facilitates a person speaking to himself in anticipation of the reaction of others, in their absence.

> “Mentality on our approach simply comes in when the organism is able to point out meanings to others and to himself. This is the point at which mind appears, or if you like, emerges. It is absurd to look at the mind simply from the standpoint of the individual human organism; for, although it has its focus there, it is essentially a social phenomenon; even its biological functions are primarily social” (Mead, 1962).

In this way, the person in rehabilitation can develop within himself through reflexive psychological development through interactions with others. Mead (1962) captures this requirement of reflexivity

> “It is by means of reflexiveness-the turning back of the experience of the individual upon himself—that the whole social process is thus brought into the experience of the individuals involved in it; it is by such means, which enable the individual to take the attitude of the other toward himself, that the individual is able consciously to adjust himself to that process, and to modify the resultant of that process in any given social act, in terms of his adjustment to it. Reflexiveness, then, is the essential condition, within the social process, for the development of mind” (Mead, 1962) p134).

According to Mead (1962), the internal dialogue is created by a dual character of the mind, the “I”, (the origin of independent, creative and non-reflective action) and the “Me” (the object of self-awareness that can only be known through reflection which positions the person within a role). For example, a person may be admitted to a rehabilitation facility. This is the “Me”. The practitioners in the rehabilitation facility will expect the patient to behave as a patient and there are certain acts that can be anticipated that reinforce those expectations. Examples include, that the person remains available for rehabilitation during his stay and that he takes part in rehabilitation activities. However, the exact procedure of rehabilitation, at a particular time, will not be known by the “Me” in advance. The rehabilitation, or other, event is mediated by the “I”, the unique and creative “I,” that forms the other part of the self and makes unique contributions. It is the “I” that is responsible for new understandings that may be incorporated into the “Me”. In this way, within pragmatism, Mead (1962) gives importance to the way the individual’s world is defined and interpreted through group life, where action is moderated through social processes (Lal, 1995).

This position reflects the emphasis of this current research. The research is concerned with the capture of the development of each participant through the interactions they have with others, the external dialogues, and the resultant internal dialogues (reflexion) as new understandings are developed through cognition and action.

Mead (1962) called this position of self as a product of social interaction refined through an on-going process of participation in society, “Sociality”. This idea is in opposition to the more sociological functional view that individuals are determined by the societies in which they live (Merton, 1973). Mead (1962) also asserted that reflection and reflexion are not the only ways the world is interpreted. Background beliefs and assumptions that are not raised to self-consciousness, described as the sub-conscious, are reacted upon as a biological individual, as opposed to a thinking individual with raised awareness.

> “The immediate experience which is reality, and which is the final test of the reality of scientific hypotheses as well as the test of the truth of all our ideas and suppositions, is the experience of what I have called the “biologic individual.”…[This] term lays emphasis on the living reality which may be distinguished from reflection…. Actual experience did not take place in this form but in the form of unsophisticated reality” (Mead 1939).

These ideas are reflected in the Intermediate Care unit as the older person attending the rehabilitation unit brings a lifetime of experiences and expectations that have been tried and tested in his “lifeworld”. Some of these may be more difficult to change by reflexion than others. Similarly the health care staff bring life and professional experiences that may make action based on prospective reflection and reflexion more difficult. This current research assumes that people are not so socially fixed and they do develop through personal reflexion as described within hermeneutics and pragmatism.

The development of self through interaction demands the use of symbols meanings and definitions derived from the social world. Reflexion and interaction and the use of these symbols are assumed within the research methodology, symbolic interactionism (Denzin, 1970).

Symbolic Interactionism

The internal and external dialogic nature of the development of self through the contextual interaction with the “I and “Me”, discussed within hermeneutic phenomenology and pragmatism, above, was termed symbolic interactionism (Mead 1962). However, these ideas were first used in research, as a methodology to study meaning derived from social situations, by Blumer (1969). Blumer (1969) expounds three premises that facilitate the examination of the social world, are rooted in pragmatism and are the basis of symbolic interactionism. These are that

> “Human beings act towards things on the basis of the meanings that the things have for them. The meanings of such things are derived from or arise out of the social interaction that one has with ones’ fellows. These meanings are handled in, and modified through, an interpretive process used by the person dealing with the things he encounters” (p2).

These premises mean that individuals operate in society to create meaning and reality for themselves through social interaction. (Denzin, 1970, Charmaz, 2006). Therefore, as a research approach, symbolic interactionism takes as a tenet, that the self is constructed and reconstructed through social interaction and not just through individual thought (Klunklin and Greenwood, 2006, Jeon, 2004, Priest et al., 2002).

In this current research, at the start of rehabilitation, each participant had different understandings of the nature of rehabilitation as it related to them as individuals. Many of these understandings remained different for each participant throughout their rehabilitation, even though they communicated with the same group of staff. It was how these differences developed through interaction that provided data, and, after analysis, information about the meaning of involvement, created through symbolic interactionist processes.

From a symbolic interactionist perspective, the benefits of interaction occur when a person is able to see himself from the position of others. When this happens, the symbols used in the interaction, will be known and understood in the same way by the actors. Within symbolic interactionism the emphasis on social interaction provides a theoretical foundation to construct meaning in social situations, such as those provided during the rehabilitation of older people in an Intermediate Care unit.

A researcher, working within symbolic interactionism, must find ways of capturing the interactions and individual thoughts from different data sources, so that meaning can be constructed. Blumer (1969) states that within symbolic intractionism

> ”The only way to get this assurance [that interpretations are empirically valid] is to go directly to the empirical social world-to see through a *meticulous examination* of it whether one’s premises or root images [ideas], one’s questions and problems posed for it, the data one chooses out of it, the concepts through which one sees and analyses it and the interpretations one applies to it, are actually borne out” (Blumer 1969 p32).

For this current research this means that, in order to collect useful data about the involvement of older people in their rehabilitation after acute illness, the researcher must work in that social world, the environment where rehabilitation of older people takes place.

Within the relevant social world being able to ascribe meaning to involvement in rehabilitation will depend on the ability of the researcher to capture the ways older people and the practitioners ascribe meaning to their social products, based on language and behaviour (Klunklin and Greenwood, 2006). This is challenging because, as discussed above, meaning will vary for each older person in rehabilitation, as they present their life experiences, expectations and abilities to the social arena. It is also likely that initial meanings will change for the older people and staff, over time, as rehabilitation progresses and the older people learn about their rehabilitation.

Conducting a scientific study into the meaning of involvement in the rehabilitation of older people after acute illness, using an approach that has a relativist ontology and a constructivist epistemology, and is managed through symbolic interactionism contains several premises (Charmaz, 2006). Firstly, there is an assumption that individuals, including the researcher, bring and use their own experiences within the research and react to phenomena in a potentially unique way. Second, there is an acceptance that language and behaviour are representations of the conscious mind in the description of experiences of involvement. Thirdly, there is an acceptance that the meaning of involvement can be constructed from the description of experiences of older people and practitioners in rehabilitation. Fourthly, there is an acceptance that these experiences can be captured through the scientific study of the interaction with people through language and behaviour and indirectly through the analysis of interviews and conversation transcripts.

Using the premises above and accepting relativism as the ontology and constructivism as the epistemology, the term, “Constructions” has been chosen purposefully as the title of chapter six replacing more traditional terms such as “Findings” or “Results”. Both Findings and Results, as chapter headings, would have indicated that the research objective was to find something that was there to be found before the research took place and, as a result of the research, was discovered. The constructivist, symbolic interactionist approach employed in this research, declares that, the research is grounded in the data and the meanings given to the data have been constructed through interpretation in the course of the data collection-analysis process. However, the term “findings” has been used in the abstract to aid understanding at the start of the thesis.

There are examples of research that have used symbolic interactionism as a basis for research. Williams (2009) developed an understanding of how people with Parkinson’s disease forged social bridges and scaffolds to maintain stability in their lives. Additionally, Klunklin and Greenwood, (2006) used the explanatory power of symbolic interactionism to explain the social experiences of married and widowed Thai women with HIV/AIDS. Grounded theory, consistent with constructivism, pragmatism and symbolic interactionism provides the methodology for this current research.

This development, described above, demonstrates the importance of language on experience. Gadamer (1975), in agreement with Heidegger (1962), stated that

> “Language is the universal medium in which understanding occurs” (Gadamer 1998 p389).

(Gadamer, 1975) described hermeneutics as

> “The art of grasping what someone really wanted to say” (p 133).

However, grasping what someone really wanted to say is complex as all statements are representations. Additionally one cannot assume that what is said is an accurate representation of what was wanted to be said. Therefore, research based on dialogue will also be an interpretation of a representation (Bonner, 1994) and that representation is not absolutely verifiable,. This leads to the concept of prejudice in representation and interpretation. The representations within language and interpretations will include some of the historical, social and cultural background of the interactionists and these add prejudice to the research (Koch, 1995, Gadamer, 1975, Ortiz, 2009, Binding and Tapp, 2008).

Prejudice may be classed as useful when it aids interpretation, for example, I bring a health background which includes the care of older people and experience in hospitals as a nurse over a career lifetime. This is discussed in detail under theoretical sensitisation later in his chapter. The prejudice I bring to the research may also be classed as useless when it has no bearing on the research or pernicious when this leads to a poorer understanding of the involvement of older people in their rehabilitation in an extreme subjectivist approach. The acceptance of useless or pernicious prejudice into the research, brought by the researcher may be reduced, by the research procedures. These are the openness to learning, the rigour and transparency of the research procedure, the preparation processes prior to commencement of the research and the critique of others. In this way the understanding of the meaning of involvement will rest within a community of knowers (Bonner, 1994). This is discussed more fully later in this chapter.

The primary emphasis of hermeneutic phenomenology is the personal lived interpretive experiences of the participants (Bryman, 2008). When an individual arrives in the Intermediate Care unit that person may have varying knowledge and expectation of the way he, or she, will be managed in the rehabilitation environment. Experienced staff will have met various types of people and have some expectations of abilities, but they are unlikely to have met these particular older people prior to admission.

In this way both practitioners and older people have the opportunity to learn together about the nature of rehabilitation, building up this knowledge through interaction, using vocal and behavioural gestures as vehicles. In this current research, whilst the hermeneutic processes of the individual are important, of more importance is the capture of the meaning of involvement conveyed through the interactions between the practitioners and the older people in the rehabilitation environment.

Grounded Theory as a Method of Theory Production Consistent with Pragmatism and Symbolic Interactionism

The term Grounded theory was coined in the publication “The discovery of grounded theory” (Glaser and Strauss, 1967) and is the name given to a research approach and the product of research (Charmaz, 2008). Grounded theory is congruent with pragmatism and symbolic interactionism because all three concepts contain the premise that people make sense of themselves, and their social world, through the process of interactions with others and reflexion. They also share the premise that these interactions can be captured in language and behaviour (Charmaz, 2006).

The associations between grounded theory and symbolic interactionism have been described by Klunklin and Greenwood (2006), who make two main points. Firstly, that both the principles of symbolic interactionism and grounded theory relate to the direct examination of the empirical, social world analysed through a system that begins with induction and moves to a hypothetico-deductive scheme. Secondly, Klunklin and Greenwood (2006) point out that the twin research components of exploration and inspection (Blumer, 1969) are facilitated by the flexible responsiveness found in theoretical sampling (exploration), the constant comparison of the data (inspection) and the conceptualisation of meaning checked against the data (inspection). The characteristics of symbolic interactionism, grounded theory and the current research have been tabulated to demonstrate these relationships in Table 4.1.

Table 4.1 The Relationship between Symbolic Interactionism, Grounded Theory and the Current Research (Adapted from Klunklin and Greenwood (2006)

Characteristics of Symbolic Interactionism	**Characteristics of Grounded Theory**	**Characteristics of this current research**
Preparation		
An understanding of an aspect of the social world	An understanding of an aspect of the social world	The social world includes reflexion and interactions in the rehabilitation environment.
Exploration		
Direct observation within the empirical social world to be researched	Observing and capturing interaction, participation observation: interviewing document analysis: video taping	**Research methods** Recorded interviews and conversations in the Intermediate Care unit.
Gathering of data through disciplined observation	Observation, interviewing and the use of guidelines Theoretical sampling	Devising interview questions for the purposive sampling of the first participant designed to increase the opportunities for the capture of meaning. Theoretical sampling through the analysis of interviews and the development of questions. Checking of data as the interviews progressed facilitating conceptualisation. Recording of conversations. Checking the meaning with rehabilitation specialists during analysis.
Construction of categories	Open coding, axial coding conceptual coding, the consideration of properties and dimensions of the codes	Open coding, memoing, diagraming The development of initial categories. Constant comparison of the data. Reduction of the data to Figures and Tables. Theoretical coding Repeated checking and coding against the data and interactionists

(This table is continued on the next page)

Table 4.1 The Relationship between Symbolic Interactionism, Grounded Theory and the Current Research (Adapted from Klunklin and Greenwood (2006) (Continued…)

Characteristics of Symbolic Interactionism	**Characteristics of Grounded Theory**	**Characteristics of this current research**
Constructing and Testing Theory		
Raising of abstract problems	Personal memoing	Asking questions of the data and constant comparison Developing ideas recorded as memos and Figures, associating theory to social principles
Construction of a theoretical scheme	The formation of categories subcategories, properties dimensions memos and figures	The development meaning linked through codes, categories and their properties. The production of an audit trail
Testing of categories	Theoretical sampling theoretical saturation literature review group analysis member checks	Literature review Member checking (Participants and Practitioners) theoretical saturation/ data sufficiency

This current research is concerned with the formation of a substantive theory, as opposed to a formal or universal theory. Whilst the substantive theory may not be generalised to more universally-based, sociological theories, it is nevertheless valid (Glaser and Strauss 1967).

The grounded theory production process, in-line with other qualitative research analysis, involves the collection of qualitative data and its analysis by fragmenting the data and coding the fragments. The data are then re-constructed in innovative ways into interlinking themes and categories facilitating a new description (Walker and Myrick 2006). This is done by, for example, comparing the codes looking for differences and similarities. The final more conceptual stage is the development of conceptual categories and the substantive theory.

The Difference between Original Grounded Theory and Constructivist Grounded Theory

Original grounded theory is developed using an initial inductive approach (Morse, 2001) in which the researcher sets out to discover meaning through systematic exploration and inspection of the data (Walker and Myrick, 2006, Klunklin and Greenwood, 2006). In this original form of grounded theory the author was seen as the “distant expert” (Mills et al., 2006b), commensurate with a realist ontology. This ontological position required Glaser and Strauss (1967) to reify the data, that is, see the data as containing an objective and discoverable truth (Bonner, 1994). This made the realist ontology, coherent with the constructivist (made realist) epistemology. Managing the data in this way, Glaser and Strauss (1967) took a position along the realist-relativist continuum towards realism.

Since that time the grounded theory approach has been adapted, for example, by Charmaz (2006), who takes a position along the realism-relativism continuum, further towards relativism within constructivist grounded theory. Charmaz (2006) describes grounded theory as a set of principles emphasising the procedures, first discussed prescriptively by Glaser and Strauss (1967), as *guidelines*. Charmaz (2006) uses an inductive, interpretive approach, consistent with pragmatism and symbolic interactionism

> “To construct grounded theories through our past and present involvements and interactions with people, perspectives and research practices” (p10).
>
> “I assume that neither data nor theories are discovered. Rather we are part of the world we study and the data we collect. We *construct* our grounded theories through our past and present involvements and interactions with people, perspectives and research practices” (Charmaz 2006 p10).

When Charmaz (2006) writes “We are part of the world we study” it demonstrates that she is working within pragmatism and symbolic interactionism, from the ontologic position of relativism and epistemologically in interpretation. Charmaz (2006) demonstrates a constructivist understanding of the way the researcher is engaged with the data which is different from that of the original form of grounded theory (Bonner, 1994). Charmaz 2006) wrote

> “Any theoretical rendering offers an *interpretive* portrayal of the studied world, not an exact picture of it” (Charmaz 2006 p10).
>
> “Research participants’ implicit meanings, experiential views-and researchers’ finished grounded theories, are all constructions of reality” (Charmaz 2006 p10).

Walker and Myrick (2006) also recognised this constructivist approach, defining grounded theory as…

> “A simple and complex, methodical and creative, and a rigorous and laissez-faire process in which the researcher engages to generate theory from the data”. (p 548)

In addition to the comments of Walker and Myrick (2006) grounded theory research is inductive as the researcher starts with no formal hypothesis to test and yet is hypothetico-deductive in the choice of subsequent data-sets as the research progresses, through the use of theoretical sampling (Corbin and Strauss, 2008). Xuan-Yi et al (2009) produced a substantive grounded theory about the practices of home-based hospital care of severely mentally ill people in Taiwan. This research can be used to demonstrate the above characteristics of grounded theory.

Grounded theory is simple, in terms of the accessibility of the method to the researcher, and yet complex in the thought processes behind the procedures. In Xuan-Yi, (2009) the complexity included the recognition that there is a need for a substantive theory in this area of mental illness care. Additionally, thought had to go in to: how participants were to be recruited and data collected, stored and theory generated the management of the literature and sensitisation. This requires belief that the work can be done, a hope that the data required will be available (Glaser 1978), and a willingness to self-scrutinise and facilitate the scrutiny of others to reduce pernicious prejudice.

Grounded theory is methodical, as the researcher codes, compares and classifies the data as part of the exploration and inspection. However, grounded theory is also creative as, for example, Xuan-Yi (2009) altered the interview guide, after the first interview and analysis, and the researchers worked interpretively, organising the data and choosing participants through theoretical sampling as the analysis progressed.

Grounded theory is rigorous and thorough. Xuan-Yi (2009) generated large amounts of data required to be analysed. At the same time, grounded theory is *laissez faire.* This is concerned with the individual creativity of the researcher as interpretations are made about the data. Lastly, grounded theory is inductive and hypothetico-deductive. The first participants in the Xuan-Yi (2009) study were chosen, inductively, from a group of people with the characteristic of severe mental illness. Subsequent participants were chosen using deductive reasoning to confirm (or discard) the emerging theory.

The Distinctive Features of Grounded Theory

All grounded theory studies encompass a number of concepts in common with other qualitative research approaches, such as data collection based on qualitative forms, fragmentation of the data and innovative reassembly (Backman, 1999). However, there are two concepts that define grounded theory. These concepts, briefly described above, are a constant comparison of all the data throughout the data-collection-analysis and theoretical sampling. In this current research a combination of purposive, maximum variation and theoretical sampling was used within the sampling strategy. These forms of sampling and their general use will be discussed here and more specifically related to the current research, later in this chapter.

Constant Comparison of All the Data at each Stage of the Data Collection-Analysis

The grounded theorist collects and analyses data in combination rather than separately (Charmaz, 2006). Part of the-analysis is a constant comparison of older data with newer data and is carried out at all stages of the data collection-analysis (Backman, 1999). In practice this means that new data, is compared with all other data from initial coding right through to emerging constructions and theory development (Mills et al., 2006a). This data collection-analysis method increases the likelihood that the interpretations of the researchers are based within the data and the meaning ascribed to the constructions is represented in the whole of the research data.

As the data collection-analysis proceeds, the increasingly complex analyses are used to direct further data collection, analysis and comparisons of data which gives rise to a sampling technique called theoretical sampling (Polit et al., 2001). In this current research a constant comparison of the data was managed during the data collection-analysis of each participant and between participants and is discussed later in this chapter.

Purposive, Maximum Variation and Theoretical Sampling

Purposive sampling

Purposive sampling or purposeful sampling, used in qualitative research, is sampling based on the personal judgement of the researcher concerned with ensuring that the research is productive (Polit et al., 2001).

Purposive sampling is concerned with the identification of useful and accessible settings, populations and individuals where research phenomena are likely to occur. For example, Reis et al (2007) used purposive sampling to identify barriers and facilitators for the implementation of low back pain guidelines. The sample was purposive because it was based on the characteristics of the participants. In this case, all the participants were family physicians and, importantly, the decision to choose this characteristic and the participants, was decided before the start of the research.

Purposive Sampling of Older People as Participants in Research

Part of the purposive sampling strategy before the start of this current research was to define "older people". A definition of "older people" requires some characteristic that all people in the group share. The range of cognitive and functional abilities of people at most ages is too variable to use as a set of characteristics and may reduce the numbers of older people, suitable for the study, unnecessarily. One characteristic that all people share is the age a person may become eligible for a state pension in a given context. In the UK this is currently under review. (Department of Work and Pensions, 2011). However, until recently, the relevant age has been 65 for men and between 60 and 65 for women depending on their date of birth. In this current research, 65 or over was used as the definition of older people. Other studies have used 65 as a chronological point to define older people, for example, Slater and McCormack (2005, 2004) and some have used 60, for example, Gretarsdottir et al (2004). These studies used their definitions for no particular published reason. All the older people participants in this current research were over sixty five years with an age range from 72-86.

Maximum Variation Sampling

A variation of purposive sampling, relevant to this research, is maximum variation sampling (Polit et al., 2001). This sampling strategy sets out to purposefully select participants who provide the widest range of variation within the selected criteria. For example, Peterson et al (2008) assembled a demographically diverse cohort of 61 patients who had been successful or unsuccessful at post-angioplasty multi-behaviour change. Maximum variation sampling achieved the widest variation of reported perceptions and behaviours. Importantly, maximum variation sampling, as a purposive sample, involves the choice of variation being made before the start of the research.

Theoretical sampling

Theoretical sampling, another variation of purposive sampling, is an integral characteristic of grounded theory research (Charmaz 2006) which directs the research towards the development of theory as the researcher follows leads emerging from the data analysis. These leads direct the research to further samples, which it is thought will assist in the development of theory (Morse, 1995, Dey, 1999). This differs from other forms of purposive sampling where the characteristics of the participants are devised before the beginning of the research. Hence, the requirement for some belief and hope, at the start of the research, that the data will be available, discussed earlier in this chapter. This position represents the creative part in Walker and Myrick's (2006) definition of grounded theory (discussed above). In this current research, maximum variation and theoretical sampling were used in conjunction, based on the data analysis and emerging theory. This is discussed in detail later in this chapter, but for now, older people as potential participants were invited to take part in the research on the basis of what they said about their aspirations for the rehabilitation, in relation to previously recruited participants.

There are some challenges using theoretical sampling from an ethical perspective. Sample sizes and the characteristics of the participants in the sample have to be defined before ethical approval for the research is given. This process, the antithesis of theoretical sampling, may require the researcher obtaining further ethical approval, during the research, to satisfy the demands of theoretical sampling.

In an attempt to circumvent the need to return to the ethics committees for approval of a revision of the number of participants, the number of participants put to, and approved, by the ethical committee was five. This was two more than originally anticipated, itself a judgement based on the time it would take to complete the research and other studies. Other similar studies that have used similar sample sizes include, Kjerski, Nygard et al (2008) who used a sample of three older people to investigate the experiences of participation in occupation during home-based rehabilitation. However, others report that typical grounded theory studies have sample sizes between 10 to 60 persons (Starks and Brown, 2007). In this current research, it can be argued that there were 40 opportunities to collect data. Additionally, the longitudinal nature of the data collection-analysis associated with theoretical sampling and constant comparison, increased the usefulness of the data collected as the collection progressed and increased the opportunities for data saturation.

Data Saturation within Theoretical Sampling

Morse (1995) described data saturation as “data adequacy” (p147) the time when researchers

> “Have enough data to build a comprehensive theory and convincing story” (p148).

The basis of *enough* data is concerned with the need to capture the range of data to satisfy the research question from the data available. This presents a difficulty for a grounded theorist who understands that a substantive grounded theory is never complete (Glaser and Strauss 1967). Using grounded theory, theoretical sampling moves towards saturation in a creative way as the developing concepts are identified and decisions about further samples are made as the research progresses. At saturation, the researcher is required to be convinced and to be able to convince others, that there is enough data to build a comprehensive narrative within the limitations of that substantive theory (Glaser and Strauss 1967). These others include the readers of the theory, the scientific community and those working in the area who would recognise the theory as useful.

The difficulty of knowing when data saturation is achieved, has been expressed by Dey (1999), who was concerned how a qualitative researcher could ever be sure that saturation had been reached. He demonstrated this by coining the term “data sufficiency”. Having sufficient data, as opposed to enough data, may achieve the same objective, but when constructing a grounded theory, using a relativist ontology, data sufficiency seems to be a more accurate and less arrogant expression.

Theoretical Sampling the Use of "Cases" in this Current Research

There are some similarities between this current research and Case Study research. Case studies offer a vehicle for an exploratory study into the nature and purpose of involvement of older people because older people can spend a number of weeks completing rehabilitation after illness.

According to Yin (1999) a case study

> "Is an empirical inquiry that investigates a contemporary phenomenon in depth and within its real life context especially when the boundaries between phenomenon and context are not clearly evident" (p18).

Additionally, the constructivist approach used in this research does have the need for a chain of evidence (Yin 2009) in common with a case study approach. However, although this current study complies with the definition above, being a contextual exploration of a contemporary phenomenon, the involvement of older people in their rehabilitation is not suitable for a formal case study approach.

The use of constructivism to develop a sophisticated understanding of involvement precludes defining a "case" before the start of the research which is required in case study research (Yin, 2012). Yin (2012) does suggest that, within case study research, the researcher may consider redefining the case after "collecting some early data" (p6) and states that this might lead to the need to review different literature and revising interview questions. However, this current research is different from case study research because in the former, reviewing different literature and revising interview questions, during the research, were integral to the research and was not conditional, as in the latter.

Data Management Issues in Qualitative Research

Within constructivist grounded theory, there are also some data management issues that need to be addressed. These issues include theoretical sensitivity, the management of sensitising experiences and the management of the research literature (Charmaz 2006, Walker and Meryck 2006).

The Management of Sensitising Experiences

Theoretical sensitivity is a multidimensional quality concerned with the level of insight and ability a researcher uses to unravel the complexities of interpretations (Bryman, 2008). This quality is used to make decisions about useful, and not so useful, interpretations that might come from the data (Strauss and Corbin 2008). This was discussed briefly in the hermeneutic phenomenology section in this chapter concerned with prejudice. Sensitising concepts are the attributes of the researcher, such as knowledge, experiences and the way these are managed, that might alert a qualitative researcher to relevant concepts within the data collection-analysis.

The reification of the data by the original grounded theorists Glaser and Strauss (1967) forced the grounded theorist to attain theoretical sensitivity from the data alone. Using a relativist ontology, an interpretivist, constructivist epistemology, this framework considers that the constructions, (chapters five to ten) are only one interpretation of data that itself is an interpretation of what was happening during the data collection-analysis period (Charmaz 2006). This leads to an acceptance that experiences are generally useful, in line with the earlier discussion on prejudice, in this chapter.

Strauss and Corbin (2008) discuss techniques that might help a researcher come to know and think about the data in different ways, such as the “flip flop” technique which helps the researcher come to understand what a particular research idea does not mean as well as what it does mean. The idea behind this is to create ways of interpretation that help the researcher focus on the best interpretation. Glaser, (1992) has argued that techniques like “flip-flop” force the data, that is, help the researcher read into the data some concepts, ideas or interpretations that are not present. Strauss and Corbin (2008) reject this discussing the techniques as useful methods of coming to know the data and complement personal strategies a grounded theorist may use.

The point of this argument is ontological and epistemological. If the data is reified and the endpoint is an objective truth, there can only be one (or no) interpretation. From a constructivist’s perspective, there can be many interpretations, but the final interpretation is eventually controlled by the results of the constant comparison of data with data. This occurs at the end of a rigorous process which must make sense to the researcher, participants and the wider scientific community.

Personal Sensitisation to this Current Research

The relevant sensitisation to the research includes my:

- work as a nurse in hospitals and nursing homes
- understanding of different approaches to care, such as individualised, person-centred and relationship-centred care,
- knowledge of patient and public involvement
- experiences of the rehabilitation of older people from the perspective of a relative.
- work as a nurse teacher, as a health care practice developer and a senior lecturer.

This sensitisation provided useful prejudice, for example, it facilitated access to discussions with health care staff and made explanations easier, for example, to staff and the older people, who were potential participants. I was also sensitised to the data and understood the prejudice I was bringing to the data collection and analysis. For example, my background alerted me to the use of cognitive learning, over operant learning in rehabilitation (discussed in chapters, eight and eleven). My background also helped me to understand the time pressures that the staff were under at work, facilitating my approach to them, concerning presentations and asking questions about older people, at appropriate times.

Sensitisation Related to the Management of the Research Literature

Traditional grounded theorists do not review the research literature, prior to the research, in order to avoid sensitisation which might influence the researcher by introducing prejudice, for example, in data sampling, collection and analysis (Glaser, 1992). However, constructivist grounded theorists argue that this information would usefully inform the data collection and analysis, as discussed above (Corbin and Strauss, 2008, Charmaz, 2006). For example, knowledge of older people care models concerned with relationships would enable the researcher to situate involvement indirectly within the research questions. All personal knowledge has the potential to influence the research; sensitisation alters only the point of departure, at the start of the research and not the research outcomes, which are based within the data.

By accepting sensitisation as a tool, rather than something to be avoided, constructivist grounded theorists accept that a researcher cannot approach question writing, data collection and analysis objectively. Constructivists accept that the researcher's views will be found in the research constructions, whether the literature is reviewed before or after the study (Charmaz 2006). The use of an open not-knowing approach (Brechin et al., 2000) and a desire to learn from the situation is the starting point. In this current research, knowledge of the literature grew as the data collection-analysis progressed and was useful to help make interpretations that fit the context and develop theory.

To exemplify the effect of the literature on theoretical sensitivity, the paternalism and rhetoric, described in some implementation of patient involvement literature, discussed in chapter two, Background, helped me to recognise paternalism in the interview and conversation transcripts. This was used to identify and reflect on paternalistic communication and action, led by the staff, which reduced opportunities for creative learning within rehabilitation and promoted passivity in the participants. Paternalism was particularly noticeable during the data collection, related to some of the conversations recorded between members of staff and the participants. An extract from a conversation is provided in Appendix Two.

Additionally, the literature on models of rehabilitation, for example, (Eshun, 1999) helped me to reflect on paternalism and understand that within the data, there was evidence that some staff made complex decisions which went unrecognised. These decisions were made frequently each day, about how and when to help a person in rehabilitation and when and how much to let them do things for themselves. The decisions were made more complex because each day, the participants were able to do more for themselves. This complexity was not recognised by the staff and, frequently, these decisions were left to those least experienced or trained to make them, for example, support nursing staff. This represents an example of a wider invisible contribution of nursing generally (Lawler, 1991).

In this way, although the data led the constructions, the literature and my experience formed part of my sensitisation towards the data collection-analysis. This facilitated deduction, selection and interpretation during the building of a substantive grounded theory, understandable by the participants and relevant to the staff.

The theoretical framework described above and consisting of a relativist ontology, a constructivist epistemology and a grounded theory methodology was used to progress the production of a substantive theory about the meaning of the involvement for older people in their rehabilitation after acute illness. The features of each component in the hierarchy inform and constrain the others. The chosen methodology, grounded theory, based within pragmatism and symbolic interactionism, uses the premise that individuals within groups develop and are developed through vocal and behavioural gestures and this can be captured in a language-based research approach. The features of grounded theory, particularly the definitive procedures of constant comparison of data with data, theoretical sampling and the management of sensitising concepts, further inform and constrain the research method.

Research Method

Introduction

The research question, introduced in the conclusion of chapter three, and the methodology chosen~~,~~ requires a data collection and analysis design, that captures the interactions of a social group in addition to the thoughts of the older people and staff as individuals, over a period of time. The method is concerned with the implementation of that design.

Summary of the Data Collection

Four older people were interviewed, on three occasions, during their rehabilitation stay in an Intermediate Care unit and then once at home. Within a few days of each older person interview, a member of the rehabilitation staff, who worked closely with the older person, was interviewed and a conversation between the older person and member of staff was recorded. Overall, the plan was to collect data from forty interviews and conversations. This is summarised in Table 4.2.

Table 4.2 A Summary of the Longitudinal Data Collection Plan

Longitudinal Data Collected from Each of Four Older People and Health Care Staff.
During Rehabilitation 3 Interviews with the older person participant 3 Interviews with a member of the health care staff (who works closely with the older person) 3 Conversations between a member of health care staff and the older person during their normal work. **At home** 1 Interview with the older person at home

Total number of interviews and conversations =10x4 older people=40

This chapter begins with a discussion about the context of the research which includes the roles of the staff of an Intermediate Care unit and a demonstration of the typical progression of a person in rehabilitation, in the Intermediate Care unit. Next, a detailed discussion of the data collection plan and an explanation for the types of data collected is followed by a critical discussion about the preparation for the research, including the use of previous sensitisation which facilitated access to the research setting. The ethical considerations are then discussed, followed by the management of the data collection-analysis. Within this section, a critical discussion about how the participants were chosen demonstrates the use of the sampling strategies and data collection-analysis procedures within a grounded theory methodology.

The Research Context

The Choice of the Type of Research Setting

Silverman (2010) discusses some of the practical influences on the type of setting to be used in the research such as: the ease of access, researcher safety and travel distance. Another important criterion is whether or not the experiences of the research population are typical of the experiences of older people in rehabilitation (Bryman, 2008). These criteria were taken into account pragmatically, so that the research could be completed within the available time resources.

Based on the research question and participant eligibility criteria, discussed later in this chapter within ethical considerations, the type of research setting required was a rehabilitation unit, where at least some of the patients were aged 65 and over. Local access to the research population was preferred. The local acute hospital had an Intermediate Care unit on site where older people spent around six weeks in rehabilitation before being discharged. This length of time provided opportunities for a longitudinal study of the development of relationships between the practitioners and the participants and therefore, possible demonstrations of different levels of involvement to investigate.

The availability of a natural setting, such as this Intermediate Care unit, was important as discussed in earlier in this chapter.

The Intermediate Care unit: An Overview

The Intermediate Care unit chosen has 25 beds and is staffed by a clinical, multi-disciplinary team including physiotherapists, occupational therapists, nurses, medical practitioners, social workers and support workers. Other clinical, health and social care professionals, such as community psychotherapists, are referred into the Intermediate Care unit as required. The main groups, concerned with the research were physiotherapists, occupational therapists nurses and support workers.

The aim of the staff, taken from their unpublished service directory, (Appendix One) is to achieve the

> "Best achievable function and maximal attainable physical, psychological, social function and independence".

Decisions about the rehabilitation of older people are effected mainly through weekly multi-disciplinary team meetings. At these meetings each patient is discussed, firstly from a medical perspective and then from functional and prognostic perspectives.

Older people who are admitted to the Intermediate Care unit are medically stable, which means that they do not have an acute illness that would warrant investigation or the instigation of new treatments. This is necessary as the primary role of Intermediate Care services is rehabilitation; medical treatment is a secondary, related role.

There are policies and processes in place that guide those health care practitioners who admit older people on to the Intermediate Care unit. This was summed up by an occupational therapist who assesses people for rehabilitation

> “People, before they, erm are admitted to the ward, they are assessed and they are told what the ward is about. They actually have to consent to come into the ward and taking part in rehabilitation.”

The part of the assessment, the occupational therapist referred to is the application of exclusion criteria, concerned with the smooth running of the unit and the ability of the potential older person to benefit from rehabilitation. These exclusions are people who: have the potential for disruptive and challenging behaviour, require mental health services as a primary need, those who might wander and people who require respite care. It was believed that the possession of these characteristics would preclude rehabilitation (Appendix One).

The older people in the Intermediate Care unit are therefore a select group and do not represent a random selection of older people recovering from acute illness. However, they do represent a group of people who typically respond to rehabilitation (Bryman 1988).

The Rehabilitation Process

The Work of the Physiotherapists and their Support Workers

Although the physiotherapists take the lead with their clients, they work *with* the older person. A physiotherapist discussed this

> "If you try to get them to do something they don't understand or why you are doing it, they won't believe it's necessary. It's never going to work".
> "It always needs to be a process where you're working with them and so they understand every step of the way why you are doing something".

Older people have around half an hour to one hour physiotherapy per day. This may seem a small amount, but the physiotherapists have other responsibilities that take them away from the Intermediate Care unit during the day. Additionally, when physiotherapists are absent, for example, on holiday or due to sickness, there may not be full physiotherapist staffing. In mitigation of this it was thought that some of the older people in the Intermediate Care unit may not have the stamina to do more than one hour physiotherapy each day. Although the older participants in this current research were physically weak at the start of their rehabilitation, there was no evidence that a lack of stamina would preclude more physiotherapy than that on offer. Many of the people in rehabilitation were encouraged to work on exercises independently. The first participant said of the physiotherapists

> "If they've got new patients in like, they used to concentrate on them."
> "And they would maybe give you 20 minutes but if they were quiet you could go for half an hour and three quarters of an hour. They used to put you through your paces."

This is discussed in the constructions, chapter nine (Risk Management).

The Work of the Occupational Therapists

The work of the occupational therapists centre on assessment and facilitation of function, such as being able to wash and dress, in order that the older person can return home, as safely and as independently, as possible. This was described by one of the occupational therapists

> "We assess function rather than say, physical ability on a daily basis within their normal routine. We are very person-centred and holistic. We need to find out how they manage to get washed and dressed, build up stamina working with the physios, and manage functional transfers from getting in and out of bed. We look at a whole functional activity rather than a component of it."

The Work of the Nurses and their Support Workers

Physiotherapists and occupational therapists have specific assessment and rehabilitation functions which differ from the nursing function. Nurses and their support workers, have a role in both caring and rehabilitation. Often nurses provide care for the older person, filling in the gaps, created by the self-care deficits that the older people have when they arrive in the Intermediate Care unit. One of the older participants described an instance of this

> "I couldn't get my hand down to wipe myself you know [after the toilet] and I used to say I cannot get... don't worry about that we'll do that and nothing was a bother."

The nurses and their support workers also encourage rehabilitation. These statements by older people of their nurses and support workers demonstrate this care and rehabilitation mix.

The nurses are

> “Very kind.”... “Could have a joke….” “They know their job….” “...Nothing seemed to be a trouble to them.”
>
> “Getting waited on by 3 and 4 women at a time [laughter] they were very good, very good.” “Staff bring tea and coffee anytime.”
>
> “You rung the bell and in seconds they were there, it wasn’t as if you had to wait half an hour for them.”

On other occasions the support workers helped the participants to help themselves.

> “They used to give us the sponge like and erm, I used to do it myself to the best of my ability, but likes of my back and all that and my backside, they used to say “just get over” which was no bother to them.”

Summary of the Clinical Roles of Other Regular Members of the Multi-Disciplinary Team

Medical practitioners led the multi-disciplinary team, diagnosed illness, prescribed and monitored medical prescription and formally discharged older people from the Intermediate Care unit. The social worker facilitated structural environmental changes required, such as the provision of permanent ramps and assisted the older person with other social issues, such as finance problems.

The Multi-Disciplinary Team Meetings

Multi-disciplinary team meetings were held weekly so that the whole multi-disciplinary team came to know the progress of individual older people over time. Relevant practitioners led the discussion on individual older people. The discussions included reports on progress which led to decisions about, for example, discharge. Individual patients were sometimes referred to other professionals, for example, a psychiatrist, for information, and the team sometimes organised a planning meeting. At these planning meetings, difficult decisions were made by a wider team, which included the older person and their family. However, planning meetings were infrequent. Under normal circumstances, older people and their family were not invited to the multi-disciplinary team meetings.

Discharge from the Intermediate Care unit

Discharge was a team decision, usually effected at the multi-disciplinary team meetings. The discussion with the occupational therapist, below, highlights the team approach to decision-making. The final decision for going home, in difficult circumstances, was made by the older person, if he or she had the mental capacity to do so. The members of the multi-disciplinary team worked together, with some trust, to help the patients make progress.

The Occupational therapist said

> "If there are risks involved going home, I highlight them as part of my assessment... and feed it back [to the multi-disciplinary team]."

The occupational therapist could not say, directly, who led the decision-making about discharge.

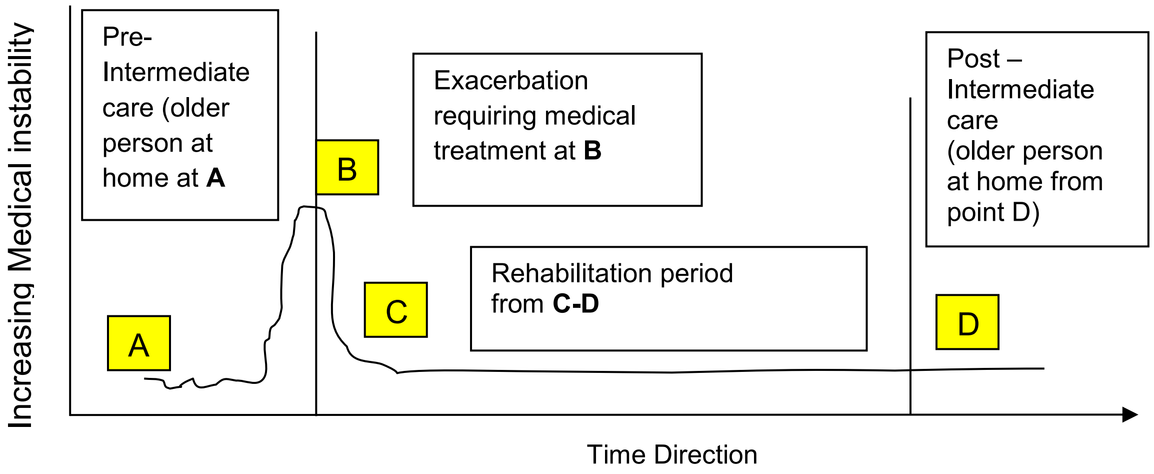
> **"How do you decide when a patient is not going to make it home?"**
> "I don't think I do decide. "
> **"Why don't you decide, or how, why is that?"**
> "Erm, if there are risks involved in going home, I highlight them as part of my assessment so I do an assessment, highlight what risks have been highlighted and erm, feed it back to the person who, you know,

> probably the discharge... not co-ordinator but, I don’t know that's a tough question.”
> “I think in terms of erm, an overriding... not decision to go home or not, but if we have huge concerns about somebody going home, the decision... not the decision, the planning of that and the planning of meetings to discuss all those things falls back to the Social Worker. If I had huge concerns about somebody’s ability to go home, obviously I would discuss it with the patient but I would also make sure that the Social Worker knew what those concerns were, for them to discuss with the patient and probably to pull together a planning meeting where I would make sure that officially and formally those risks and my concerns were highlighted. But like I said before, if that person is still saying they want to go home and they have capacity, [mental capacity] I would get them home.”
>
> “So we are looking at the person [who makes the decision] who has the predominant amount of input for that patient to be making, not making decisions but certainly having the greatest amount of input within the MDT [multi-disciplinary team].”

Typical Older Person Progression through the Intermediate Care unit

Figure 4.2 is a representation of a typical person’s progression through the Intermediate Care unit. Following the graph line in Figure 4.2, when an older person becomes ill a rise in medical instability occurs from Point A, when the person was well, to Point B when the person was medically unfit. As the older person’s condition improved, they may be admitted to the Intermediate Care unit at Point C. It was after this time, the period between Points C and D, that an older person became eligible to take part in the current research. At Point D, the person would be discharged from the Intermediate Care unit, after around six weeks.

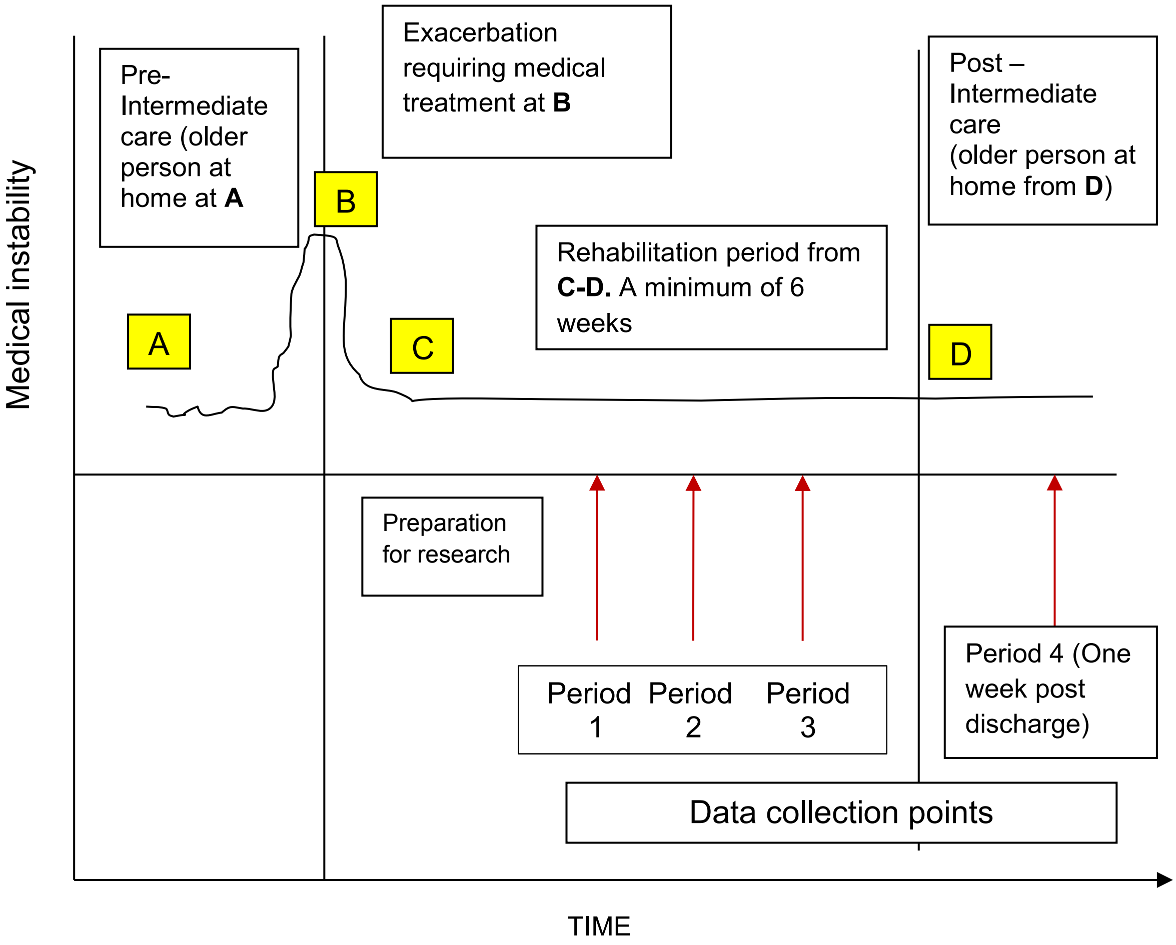
Figure 4.2 The Typical Progression of an Older Person Taking Part in Rehabilitation in the Intermediate Care unit



Data Collection Plan

In order to complete the data collection, a minimum time of six weeks was required for each participant to complete the data collection and required analysis. Figure 4.3 illustrates how the planned data collection points, map on to the rehabilitation stay and discharge from the Intermediate Care unit.

Figure 4.3 Data Collection Points mapped on to the rehabilitation stay and discharge



The data collection plan divided the rehabilitation stay (C-D) into three Periods. It was planned that each of the periods, 1, 2 and 3 would correspond to about 10 days (about 30 days in the rehabilitation period). If the rehabilitation stay was six weeks (42 days), this would allow four days from admission to the first data collection point for choosing potential participants and obtaining consent. Additionally, four days would be available between Period One and Two and between Periods Two and Three (eight days in all) for analysis. Longer Periods would have precluded data collection from many older people because they would have been discharged before the data collection was complete.

The thoughts and interactions of the older people, during each Period, were captured by a series of recorded interviews and conversations. These are summarised in Table 4.3.

Table 4.3 A Summary of the Longitudinal Data Collection Progression

Planned Data Collection Times during the Rehabilitation Stay and at home	**Data Collected from Each of the Four Older People and Health Care Staff.**
Period One (up to ten days)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Two (up to ten days)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Three (up to ten days)	1 Interview with an older person 1 Interview with a member of the health care staff 1 Conversation between a member of health care staff and the older person
Period Four (at home)	1 Interview with the older person
Total number of interviews and conversations =10x4=40	

The contiguous nature of the data collection using constant comparison of the data and analyses of the emerging concepts, provided opportunities to capture the older person's narrative throughout the rehabilitation stay and at home. Other strategies such as cross-sectional designs would not have facilitated this as successfully. However, analysis between interviews, within periods, was a challenge because of the short time available. This is discussed later in this chapter.

In the planning of the research, it was thought that the four Periods (Figure 4.3) might represent different stages in rehabilitation. These were when the older person was at the weakest (Period One) after some progression (Period Two), in preparation for discharge (Period Three) and after discharge to the “new” home environment (Period Four). Although in Period One, the participants were generally physically weaker than in Period Four, the Periods were not distinct and the participants could not be compared across the individual Periods.

Explanation for the Types of Data Collected

Overall, within the first three Periods (Figure 4.3 and Table.4.2), the data collection process was designed to capture an interpretation of the social milieu of the older persons’ rehabilitation stay. The first type of data came from interviews of about 40 minutes designed to collect the developing perspectives of each older person. The second type of data explored the specific participant’s rehabilitation with a member of staff who worked closely with each older person. This was designed to capture a different representation of the rehabilitation interactions. In the research, for three of the older people, the person who worked closely with the participant, was a member of the physiotherapy team and for the other participant, this was a member of the nursing staff. These types of data could only capture the representations based on interview questions. It was useful that this came from the two perspectives, the older person and the member of staff.

The third type of data was designed to capture how the older person and staff were involved in their rehabilitation more directly.

These conversations were recorded for a period between 20 and 40 minutes, whilst a member of the health care staff carried out their normal duties with the older person participant. This was to reduce the likelihood of recording simulated conversations. The conversations were captured in Periods One, Two and Three (Table 4.3). An extract from the transcript of one of these conversations is presented in Appendix Two.

Preparation for the Research and the use of Previous Sensitisation

Access to the Intermediate Care unit

Although I had senior managerial and ethical permission to do this current research, my health care experience helped me to understand that I could not rely on these permissions to gain co-operation from the staff. I knew that this co-operation was very important for the smooth running and eventual completion of the data collection. I also knew that once I had made contact with any of the staff, information about me and the research would start to be passed around. Therefore, in all my preliminary work prior to the research, I made an effort to speak and behave as a person who had an open mind and was confident about the research process that was about to start. Additionally, I tried to answer questions about the research in a friendly, non-threatening or defensive manner with the intention to build confidence in the staff, about the research.

Having made appointments through the medical and Intermediate Care unit secretaries, I planned to see the consultant medical practitioner and senior nurse, respectively. My experience as a manager helped me to understand that at this meeting I should: be brief and articulate in the explanation of the research, answer questions, offer a detailed explanation of the research at a later date, be confident of the research process and be able to articulate the expected outcomes. I also realised that the time specified for the appointment was approximate for the medical practitioner, but precise for me and that I may have to leave at short notice.

Neither the medical practitioner, nor the senior nurse had completed a doctorate, so I was wary that they might not fully understand the importance of the research, especially as the objectives were not specific to the Intermediate Care unit. Additionally, the results would only be published a few years hence. I believed that they might see this as a weakness of the research and that was important for me to listen and respond to this and any other challenges, as well as present my ideas.

At the end of these two initial interviews, I had explained the research, answered questions and articulated the planned roles the medical practitioner and the senior nurse would play in the research. Both these practitioners were verbally supportive of the research.

The medical practitioner was important to the recruitment of participants as I was required to have formal permission from her to recruit each older person, (discussed in the ethical considerations in this chapter). A copy of the letter is presented in Appendix Three. Additionally, both the medical practitioner and the senior nurse had a role to convey information about the research to their staff. It was important that this was done in a supportive way, as many of the staff would eventually be asked to discuss potential participants with me and some staff would be invited to take part in the research as participants.

The two discussions with the medical consultant and the senior nurse, prior to the start of the research, were also the start of my understanding about how the research would fit with the rehabilitation process within the intermediate Care unit. In a sense my involvement with the staff of the Intermediate Care unit was both determining, as I set out my plans for the research and determined by the processes of rehabilitation in the unit. This understanding developed throughout the data collection-analysis process as a process of "Sociality" (Mead 1962) using symbolic interactionist processes, discussed earlier in this chapter.

As part of the two initial interviews, I asked permission for the staff to attend a PowerPoint presentation (Appendix Four) followed by a question and answer session (around 30 minutes in all). I knew the presentation would have to be concise and that I would be reliant on this to convey main messages to the staff, about the research. I expected to have to do three presentations, but this was increased to five as the staff did not attend these in large numbers.

In some ways the increase in the number of presentations was useful because I was able to use the questions asked about my research to further develop my ideas about how the research fitted into the rehabilitation process. These ideas led to changes that brought the research process in line with the rehabilitation process. For example, initially I thought that the Named Nurse system in the Intermediate Care unit meant that each person in rehabilitation would have a key worker, who I would invite to be part of the research, as the participants were recruited. However, The Named Nurse was the shift leader only and did not have key worker responsibilities for individuals.

As a result of this, my research protocol was altered so that a wider range of people could be recruited to the project in support of the older people in rehabilitation. This change was serendipitous, as it provided a wider base from which to collect data. The presentations also helped me to begin to understand the priorities of the Intermediate Care unit and the organisation of rehabilitation within the unit.

Once the data collection-analysis started, I had several meetings with the medical consultant and senior nurse to discuss the research progress. With the medical consultant, I was able to streamline the granting of permission for the potential participants to reduce lag times, discussed later in this chapter. With the senior nurse, I was able to discuss the way the staff were managing their role in the research, which was, in turn, discussed at team meetings. These processes kept the research in the minds of the staff so that discussion about potential, and actual participants and the recruitment of staff to the research, was made easier.

The Use of Field Notes and Informal Conversations to Increase Theoretical Sensitivity

During the research there were opportunities to take field notes which, when converted into memos were helpful, later, in keeping track of the "Chain of evidence" (Yin, 1999) as the meaning of involvement began to emerge. Some of these memos are contained within the extract of a narrative of one of the participants in Appendix Five. Using the concept that everything is data (Glaser, 1978) informal conversations, and information from the multi-disciplinary meetings that I attended, were useful in increasing my sensitisation, particularly at the beginning of the data collection-analysis period.

Another example of the usefulness of field notes was the development of an understanding in the role of relatives in rehabilitation. The relatives seemed to have very little contact with the practitioners during rehabilitation, even though they played useful roles in each of the participant's rehabilitation. This incongruity was part of my developing understanding about the level of paternalism used in the rehabilitation and I began to look for the level of paternalism and other approaches to care and rehabilitation.

Associated with this paternalism was the role of the older person in the timing of their discharge. At the multi-disciplinary meetings the discharge date was set by the practitioners, based on rehabilitation progression and how the practitioners believed the older person would manage at home. The older person's involvement in this was variable, which helped me to develop questions about how the participant was involved in their discharge and what they thought of this process. In this way, leads that started in the multi-disciplinary meetings alerted me, or consolidated themes, used in the interviews of the staff and the older people.

Tension between Theoretical Sensitivity and Disengagement to find Innovative Paths in the Data during analysis.

Managing this current research, I found a tension between the use of knowledge, experience and attitude sets and the requirement of disengagement from previous understandings. As the data collection-analysis progressed there were three developing issues to manage, all of which increased the tension described above. Firstly, there was my developing sensitisation to the research topic. This was at a level before the project, as discussed earlier in this chapter, and increased as the data were collected and analysed. The second issue was concerned directly with the data. The data were developed through theoretical sampling and constant comparison as they were analysed and interpreted. The third issue was the research literature, which develops as authors publish their work, but more importantly operated to increase my sensitisation to the data as the literature was explored. This was especially evident after the conceptual codes emerged. An example of this, in this current research, was when developing an understanding of motivation from the literature, I came to understand the relationship between psychological and action-based development. Psychological developments were important but unseen whereas actions were seen and were easier to describe in health care practice. This led to a description of the Involvement Attributes as a continuum from the psychological to the active described in chapter eleven, Study Discussion.

It is the increasing sensitisation that challenges the pursuit and creation of new and innovative paths through constant comparison and theoretical sampling as the data are collected and analysed. Constructivist grounded theorists do not claim neutrality, or authority over the grounded theory process which ends in an analysis of a particular phenomenon (Charmaz (2006). Conversely, it can be argued that this absence of neutrality prevents a researcher taking an open, not knowing approach (Brechin et al., 2000).

This challenge was met in several ways and of prime importance in this respect, was the subordination of the increasing sensitisation, acquired through data collection and analysis and the associated literature, to the best interpretations of the data. The data led the sensitisation rather than the converse.

There are five other opportunities to meet this type of challenge. Firstly, the interpretations are representations of meanings conveyed, through language, by other people. Ways of checking meaning of interpretations include member checking (Guba and Lincoln, 1985). This is discussed later in this chapter associated with the data collection-analysis. In this current research, this was done using the opportunities provided by longitudinal research, to check the themes, with the participants, as the interviews progressed.

Checking the themes, as they emerged, reduced the likelihood that constructions were developed through a misunderstanding of the participants' contribution to the research. However, the time available for this checking, was short and is discussed later in this chapter and as a limitation of the research in chapter twelve (Conclusion to the Thesis).

Secondly, the interpretations should be recognised as useful by the staff of the Intermediate Care unit. This was identified by asking rehabilitation practitioners their thoughts of the constructions and analyses. Rehabilitation practitioners have read the constructions and analyses in this current research, have commented on poster presentations, do recognise the interpretations and constructions and find them clinically useful. Thirdly, steps should be taken to demonstrate the trustworthiness of this current research. These are discussed in chapter twelve (Conclusion to the Thesis) and are concerned with the rigour of the research process. Fourthly, when the constructions are published, the wider scientific community will have the opportunity to comment on the usefulness of the research. Finally, the aims of this research were to develop a deeper understanding of involvement in a specific area of physical rehabilitation. These deeper understandings may be tested using different research methods, in further research. These are discussed in chapter twelve (Conclusion to the Thesis).

Ethical Considerations

The research used the four general principles of ethics: respect for autonomy, beneficence, non-maleficence and justice, described by Beauchamp and

Childress (2001) as the ethical base. In this current research respect for autonomy was upheld as each potential participant was given enough time to come to understand the research and ask questions before being asked to provide informed consent. Additionally, autonomy was respected as the recruitment discussions progressed and the relationship with the participant developed, by checking availability and continued interest in the research project. Beneficence was managed structurally through the aim of the project, which was to develop an understanding of involvement so that, in future, this information could be used to the benefit of other people in rehabilitation through recommendations to health care practice. Additionally, a conscious effort was made to do good and no harm through the language of the interviews. Steps were also taken to do no harm by careful timing of the interviews.

Within these principles each participant was invited to take part in the research based on the evidence available that their inclusion would add to the cumulative knowledge about the understanding of Involvement. However, the choice of participant within the group of people available was narrowed by clear ethical and practical criteria, based within the four principles and described in the next section.

Ethical Approval: University, NHS Local Research Ethics Committee (LREC) and National Research Ethics Service (NRES)

Ethical approval was required, and received from Northumbria University, the Local National Health Service Research Ethics Committee and the National

Research Ethics Service (NRES) before commencement of the research. The approval letter from NRES is presented at Appendix Six.

Participant Inclusion and Exclusion criteria

The characteristics of older people who were to be invited to take part in the research were approved in the ethics committees. Based on the ethical principles described above, these characteristics are summarised as inclusion and, by default, exclusion criteria, in Table 4.4.

The Potential Need for a Translator

The population of the geographical area from which the participants were drawn is around 200,000 and those over 65 years of age account for around 40,000 (National Statistics on line, 2008). Of these 40,000, there are only around 400 not classed as White British. This means that the probability of the requirement of a translator was very low. During the research data collection period, there were no potential participants available who were other than White British and all had English as their first language. There was, therefore, no requirement for a translator to help participants to understand the research protocol. However, a translator service was available, if there had been a need for it.

Table 4.4 The Older Person Participant Inclusion Criteria and Interpretation for the Current Research

In order to take part in the research the older person should:

1	Be over 65 years and therefore an older person (being of pensionable age in the UK).
2	Be medically stable and well enough to take part in the research. This was to be decided by the medical practitioner in charge of the case and reviewed at each interview throughout the data collection period.
3	Have the mental capacity to give informed consent to participate in the research. If there was any doubt, the participant's mental capacity was discussed with the practitioner(s) who knew the older person best. If there was still doubt, the older person was to be assessed using the "Guidance To Assessing General Understanding and Capacity" document (Appendix Seven). If the older person appeared not to have enough mental capacity to understand the research, the participant would be excluded from the research. In this event, the reasons for exclusion would be discussed with the participant by the practitioner.
4	Have given informed consent after both oral and written explanations of the research. This was to ensure that those participating in the research were properly informed, understood the risks they may encounter and knew that they were consenting on a voluntary basis. Prior to each interview practitioners were consulted to check that each older person still had the capacity to give informed consent. At the beginning of each interview informed consent was re-established verbally by discussing the research.
5	Be recovering from an acute condition (being transferred from an acute hospital ward to the Intermediate Care unit and require rehabilitation).
6	Have the support of the clinicians within the multi-disciplinary team, including the medical practitioner in charge of the case (who gave written permission) (Appendix Three).
8	Have a planned or expected stay in the Intermediate Care unit, including a rehabilitation period, of at least six weeks. Periods shorter than this would not have allowed sufficient time to complete the study.

Informed Consent

Medical Stability, Mental Capacity and Wellness

It was necessary to be as certain as possible that the older people, invited to take part in the study, would be able to understand the research, give informed consent and complete their rehabilitation programme and the research. Three facets of this ability are medical stability, mental capacity and wellness. Medical stability, mental capacity and wellness were taken into account formally by discussing each potential participant with medical practitioners. The consultant medical practitioner signed a letter, confirming the opinion that the older person was physically well enough and had the mental capacity, to take part in the research (Appendix Three).

The relevant parts of the definition of medical stability, used on the Intermediate Care unit, taken from the unpublished service directory, (Appendix One) was that the older person would be

> "Unlikely to require an acute medical intervention or diagnostic intervention at the time of referral" "...Complex and frequent interventions by nurses are acceptable provided they do not prevent rehabilitation".

Mental capacity was important because each participant needed enough mental capacity, (Slevin, 2009) to give informed consent and take part in the interviews and conversations, over the whole of the research period.

In their review of the literature, associated with retention of older people in longitudinal studies, Bhamra et al (2008) identified five factors positively associated with attrition. These were being older, being cognitively impaired, having lower economic status, being less well educated and not being used to social participation.

Being older was concerned with dying during the research. Cognitive impairment was a particular concern in this current research because, although a participant may have continued to want to take part, cognitive impairment may have prevented an understanding of informed consent. The clinical staff were frequently consulted about the wellbeing of each of the participants, including levels of cognitive impairment. No serious deteriorations occurred. Other possible reasons for attrition, (Bhamra et al., 2008) were not considered.

Wellness, in terms of this research, is concerned with the continuous ability for a research participant to feel physically able to take part in the research. Some older people may feel generally unwell, at any particular time during the research, and not be able to take part in the interviews. In this current research, the fourth participant in the study was ill on the Intermediate Care unit prior to commencement of the data collection. Although the fourth participant did not leave the Intermediate Care unit during this period, data collection was postponed until the participant was well enough to take part in the research.

Securing Informed Consent of the Older People

The progress of each of the older people in the Intermediate Care unit was discussed weekly at the multi-disciplinary meetings. Attendance by the researcher at these meetings was important in the development of an understanding of the likelihood that an individual older person would be eligible to enter the study. At the end of each multi-disciplinary team meeting, potential participants were discussed with the medical consultant. If the older person met the ethical criteria, the older person was approached, introduced by the clinical staff.

At the first meeting of the researcher and the older person, time was spent gaining some understanding of the older person's attitude towards rehabilitation. On some occasions, the potential participant did not want to be concerned with research. Sometimes the potential participant was not thought to be the best person to provide the data that was required at that stage of the research. If the potential participant seemed interested in the research at this stage, met the eligibility criteria and also met the criteria for theoretical sampling, discussed later in this chapter, the research was initially discussed in a general way. This included the use and demonstration of a digital recorder, to be used to record the interviews. After this, the research forms were discussed individually, these were, the invitation to join the research as a participant (Appendix Eight), the description of the study (Appendix Nine) and the consent form (Appendix Ten). These forms were then left with the older person for about 36 hours.

At the second meeting, if the potential participant was still interested in taking part in the research and remembered the first visit, the study was described once more, making clear the roles of the participant, the researcher and the participant support roles of the health care staff. The older person was then invited to take part in the research. For those who answered affirmatively, the consent form was presented, discussed and signed by the participant.

Some older people decided against taking part in the research, sometimes at the behest of their relatives and sometimes because the interviews would be recorded. If the consent form was signed, a date for the first interview was made and, in effect, this date was the start of the research period (Period One, Figure 4.3). At this third meeting, data were collected and each of the chosen participants went on to complete the research.

Conducting the Interviews with Older People

Interviews were conducted at the participants' bedside, in private, on a date and at a time suited to them. The use of the digital recorder was explained and demonstrated each time, before the start of the data collection. At each interview, informed consent was reaffirmed by discussing the interviews with the participant. These behaviours and the friendly approach of the interviewer may be seen as part of a non-hierarchical approach to the interviews. However, it is acknowledged that this definition of non-hierarchical was based on my assumptions and was reduced through the control I had of the interview questions and the constructions (Karnielli-Miller et al., 2009).

Securing the Informed Consent and Interviewing Health Care Staff as Support Participants

Health care staff took support participant roles in the current research. Those members of staff, who worked clinically on the Intermediate Care unit and were actively engaged in the care and rehabilitation of the older people, were invited to take part in the research.

All the staff had been to one of the presentations about the research prior to commencement (Appendix Four). Having understood the purposes of the study at presentations, each member of staff was invited to read the study description designed for them. After this, if they agreed to take part in the research they signed a consent form similar to that of the older people participants (Appendix Ten). Recorded interviews of the support participants took place in one of the clinical rooms that were not being used at the time.

In addition to obtaining informed consent from the older people and support members of staff, informed consent was also obtained from those staff invited to take part in the older person/staff conversations, as they were arranged. These were doctors, nurses, physiotherapists, occupational therapists and support staff. All of these were introduced to the study and invited to join the research in the same way as other staff.

Conversations between the Older People and the Support Participants

The recordings of conversations were carried out by taping a digital recorder to some suitable furniture. During the first recording of this type, the digital recorder was taped to a wheel chair and the recording of the conversation was of the physiotherapist leading a physiotherapy session. Unfortunately, the physiotherapist had more than one person to manage during this session, so the transcription was difficult to use. Later recordings were planned so that the older person and member of staff worked alone. During the recording, the researcher left the room until the member of health care staff and older person had completed their work. Examples of occasions when conversations were recorded included: when the participant was getting up in the morning (Extract at Appendix Two), an interview with the occupational therapist, an interview with a medical practitioner and a conversation during a leg wound dressing.

Data Collection: Timing Issues

The Duration of the Participants' Rehabilitation Stay in the Intermediate Care unit

The typical rehabilitation period was six weeks, 42 days, and initially, each of the Periods within the participant's rehabilitation stay (Figure 4.3) was planned to be ten days long. The actual dates for data collection are presented in Tables, 4.5, 4.6, 4.7 and 4.8. These are significant as they show the time available for analysis between interviews and between participants. On some occasions, especially within Periods, the time for analysis was short.

The first participant's stay was 48 days, an extension of six days from the expected, and the second participant stayed for many weeks above the expected. This assisted the data collection-analysis time schedule (Tables 4.5 and 4.6 respectively). Unlike the other participants, Participant Two had her Period Four interview several weeks after the end of Period Three due to illness (Table 4.7). Participants Three and Four stayed in the Intermediate Care unit for less than six weeks and so the duration of Periods One to Three (Figure 4.3) were shorter than the first two participants (Tables 4.7 and 4.8).

Table 4.5 Data Collection Dates for Participant One, Joe

Data type	Dates of Data Collection in Periods 1, 2 and 3			
	Period 1	Period 2	Period 3	Period 4
Participant Interview	17 12 08	10 1 09	23 1 09	5 2 09
Staff Interview	22 12 09	14 1 09	30 1 09	
Participant and Staff Conversation	5 1 09	19 1 09	27 1 09	

Table 4.6 Data Collection Dates for Participant Two, Josie

Data type	Dates of Data Collection in Periods 1, 2 and 3			
	Period 1	Period 2	Period 3	Period 4
Participant Interview	2 4 09	12 4 09	26 4 09	20 6 09
Staff Interview	8 4 09	22 4 09	3 5 09	
Participant and Staff Conversation	5 4 09	18 4 09	29 4 09	

Table 4.7 Data Collection Dates for Participant Three, Gordon

Data type	Dates of Data Collection in Periods 1, 2 and 3			
	Period 1	Period 2	Period 3	Period 4
Participant Interview	20 8 09	2 9 09	6 9 09	16 9 09
Staff Interview	29 8 09	3 9 09	12 9 09	
Participant and Staff Conversation	24 8 09	5 9 09	8 9 09	

Table 4.8 Data Collection Dates for Participant Four, Jack

Data type	Dates of Data Collection in Periods 1, 2 and 3			
	Period 1	Period 2	Period 3	Period 4
Participant Interview	9 10 09	1610 09	23 10 09	5 11 09
Staff Interview	13 10 09	18 10 09	25 10 09	
Participant and Staff Conversation	15 10 09	22 10 09	29 10 09	

Lags in the Data Collection Period

There were two lag periods within the data collection period. The first lag period occurred in between the older person's admission and the start of the first Period (Figure 4.3). During this first lag period, the researcher became aware of the presence of the potential participant in the Intermediate Care unit and was given individual permission to approach the person to gain informed consent. This included written medical permission. The second lag period comprised of the time taken to organise the patient and practitioner interviews and the practitioner conversations and analyse these sufficiently to progress, Period to Period, using the grounded theory approach to the research (see Tables 4.5, 4.6, 4.7 and 4.8).

Reducing Lag Times

The multi-disciplinary meetings were held each Thursday, so it was possible that a potential participant could be admitted on a particular Friday. Using the multi-disciplinary meetings alone to find out about the admission, an older person could have been in the Intermediate Care unit nearly one week before he was discussed. Time was then needed to obtain consultant permission and informed consent, which took up potential research time.

The concern was, that if the research did not commence early in the rehabilitation period, then opportunities for data collection would be lost and the older person may leave the Intermediate Care unit before the research was complete. In order to reduce the probability of this, an informal information system was set up with the staff of the Intermediate Care unit, so that most admissions were known in advance, and those who met the inclusion criteria were identified at an early stage.

The practitioners were accurate in their estimation of the length of time required of individual rehabilitation and, using this advice, some older people were excluded from the research because their rehabilitation stay was likely to be too short for the research to be completed. Discussions with the medical consultant and other staff also took place outside of the multi-disciplinary team, which facilitated an early approach to potential participants.

The Selection of Older People using the Sampling Strategies

Using purposive sampling and maximum variation sampling within theoretical sampling, four older people, with different characteristics, became participants. However, several participants, who were invited to join the research, refused to take part as was their right. Trying to elicit reasons for refusals, made it clear that some of these people were not happy to be in the Intermediate Care service, or felt that they would not be able to contribute to the research. It might have been useful to have as a participant, for example, a person who was angry about their rehabilitation. This was not possible because they refused to take part in the study. Finding a way to capture this type of data should be part of further studies. This is discussed in chapter twelve (Conclusion to the Thesis- Testing the Theory).

Selection of the 1st Participant using Purposive Sampling

Within the ethical criteria (Table 4.4) and on the understanding that all the participants should represent typical rehabilitation patients (Bryman 1988) the choice of the first participant in the study was a personal judgement. This was a purposive decision based on the researcher's, then current understanding of the Intermediate Care unit, the rehabilitation process and how it was thought that the first participant would be able to contribute to the research in agreement with Backman (1999). The need for this reasoned, but imprecise choice, exemplifies the need to use the researcher's background knowledge, itself an interpretation, to make judgements in this inductive decision. Using purposive sampling, it was decided that the first participant would be someone who would be likely to return home and was keen to start their rehabilitation. In that way the older person would be most likely to demonstrate involvement in their rehabilitation. The choice was made based on the aspirations in rehabilitation of the potential participant. The staff of the Intermediate Care unit were asked for their advice about the potential participants using the ethical criteria (Table 4.4) and the purposive criteria described above.

The Selection of 2nd, 3rd and 4th Participants using Maximum Variation Sampling within Theoretical Sampling

Analysis of the data from the first participant, revealed some emerging, tentative categories, based on interpretations of the ten interviews and conversations over his rehabilitation period. These included a strong desire to go home as early as possible and a willingness to accept the practitioners' instructions without question and without thinking of the consequences of actions or inaction. Within this analysis the participant's vision and goals for the future were clear.

Based on this analysis, using the person's aspirations for their rehabilitation as a form of theoretical sampling, and in order to achieve maximum variation, (Polit et al., 2001) the second participant was chosen because she did not have fixed aspirations. At the commencement of the research, the second participant was wrestling with the decision to go into a Nursing Home or go home. After a period of time she, and the multi-disciplinary team, decided that the best option was for the second participant to go into a Nursing Home. Even though the second participant was unable to exercise, analysis of the data, relating to involvement, revealed different elements of involvement.

Using the same strategy of maximum variation within theoretical sampling the third participant was chosen because although the staff thought he could progress in rehabilitation, and he did improve enough to go home, he had a very weak aspiration for his rehabilitation. At the recruitment stage he showed little concern about his future and his enthusiasm for rehabilitation was poor, relative to that of the first two participants.

The fourth participant was chosen because he had strong ideas for his future. He was keen to go home and seemed to want to work hard. In addition, unlike the first participant at the recruitment interview, the fourth participant seemed to show an independence not shown by the first participant. It was thought that his needs might outstrip the resources available to the rehabilitation team.

Data Collection-Analysis Issues

Theoretical Sampling Associated with Analysis of the Interviews and Conversations

The first interview, with the first participant, Period One, was guided by the research questions devised prior to the start of the research (Appendix Eleven). Soon after the interview, the recording was checked and analysed enough to note emerging concepts and subjects for clarification, for the next interview.

Ideally the interviews would have been open coded before the next interview (Starks and Brown, 2007). This would have provided the best chance to incorporate the findings of the earlier interviews into the later.
However, although transcriptions were completed quickly, the timings between interviews and conversations, during each Period, often precluded a full analysis and facilitated oral analysis only. This oral analysis (Table 4.9) consisted of listening to the recording, interview or conversation, several times, noting the themes and leads to pursue in future interviews and developing understanding. The theoretical sampling and analysis, using developing question sets is captured in Table 4.9. A developing question set for participant four is presented at Appendix Twelve.

Moving this system through Periods Two, Three and Four, for each participant, (Table 4.9) the researcher was armed with increasingly useful sets of questions based on the analysis of previous interviews which were focussed on the emerging themes of the involvement of each participant in their rehabilitation.

Table 4.9 Question Development and Analysis Format for the Research Participants (First Participant Only)

Data Collection Period One	
Data sources	**Action Between Interviews**
1st Participant 1 Interview	At least oral analysis of the Participant One interview recording Question development for the health care staff interview
1st Health Care Staff Interview	At least oral analysis of the health care staff interview recording Question development for the participant 1 interview in Period Two.
1st Conversation	At least oral analysis of the conversation recording Further question development for the Participant 1 interview in Period Two Initial open coding of the two interviews and conversation
Data Collection Period Two	
Data Sources	**Action Between Interviews**
2nd Participant One Interview	At least oral analysis of the Participant One interview recording Question development for the health care staff interview
2nd Health Care Staff Interview	Aural analysis of the health care staff interview recording Question development for the Participant One interview in Period Three.
2nd Conversation	At least oral analysis of the conversation recording Further question development for the Participant One interview in Period Three Continued open coding of the four interviews and Two conversation

(This table is continued on the next page)

Table 4.9 Question Development and Analysis Format for the Research Participants (First Participant Only, Continued…)

Data Collection Period Three	
Data Sources	**Action Between Interviews**
3rd Participant One interview	At least oral analysis of the Participant One interview recording Question development for the health care staff interview
3rd Health care Staff Interview	At least oral analysis of the health care staff interview recording Question development for the Participant One interview in Period Four.
3rd Conversation	At least oral analysis of the conversation recording Further question development for the Participant One interview in Period Four Continued open coding of the six interviews and three conversations
In Period Four, the participant was interviewed for the last time. The analyses of the data were used for the maximum variation, within theoretical sampling of the next participant.	

Time was taken to analyse the transcribed data between the participants. These times are presented in Table 4.10. Over these periods of analysis, a better picture of how the participant related to the staff and the rehabilitation was developed, furthering an understanding of the meaning of involvement in rehabilitation and preparing for the next interviews, where necessary. Appendix Thirteen shows examples of open codes, from the interviews and conversations with Participant Four, Jack and Appendix Fourteen shows the axial codes relating to Participant One, Joe constructed after completion of his data collection and before further sampling.

Table 4.10 An Overview of the Data Collection-Analysis Process

Participant One Purposive sampling: Identification, recruitment, data collection and analysis for periods 1- 4. Use of field notes, memos and comparative analysis of the interviews and conversation texts. On-going Analysis of Participant One
Analysis of the data from participant one over Eight weeks
Participant Two Maximum variation within theoretical sampling: Identification, recruitment, data collection and analysis with the analysis of Participant One, in constant comparison.
Analyses and comparison of Participants One and Two Nine weeks
Participant Three Maximum variation within theoretical sampling: identification, recruitment, data collection and analysis with the analyses of Participant One and Two, in constant comparison.
Analysis and Comparison of Participants One Two and Three over Three weeks
Participant Four Maximum variation within theoretical sampling: identification, recruitment, data collection and analysis with the analyses of Participants One, Two and Three, in constant comparison.
Analyses of participants Three and Four with the analyses of Participants One and Two, in constant comparison.

The Management of the Data Recordings

During the data collection-analysis, the research interviews and conversations were transcribed verbatim from the recording. Each line of the transcript was numbered so that individual lines could be referred back to as part of the audit trail discussed under trustworthiness in chapter twelve (Conclusion to the Thesis). The transcripts were read through several times before open codes (Charmaz 2006), were assigned to relevant data by hand. An open code is a fragment of data, usually a few words, that encapsulates meaning in the research (Priest et al., 2002). The initial open codes contained, the words used by the participant (*in vivo* coding) (Corbin and Strauss, 2008) as far as possible. *In vivo* codes were used to reduce interpretation at this stage (Examples at Appendix Thirteen). Each code also had a coding format that was used in the audit trail.

Coding Format associated with the Open Codes

An example of the coding format is given below.

(40, 505-511)

Considering the figures from left to right 4 indicates that this is the 4th participant, 0 indicates that this was the first interview and 505-511 indicates the transcription lines within the interview. An example of the way this was used, in an original transcription, is presented below as part of a narrative for each older person participant. These narratives included all the open codes and relevant quotations.

Narrative 4.1 Part of the Narrative from which the Constructions of Participant Four were Developed

Period One

Staff Goals (Physiotherapy)

"Part of Jack's assessment in the first physiotherapy session was to see how far he could walk" (40, 505-511).

Jack did not think that the staff had any goals for him at first but he did say...

> "Just to progressively get better at walking" (40,197-198).

However the physiotherapist did have goals

> "Improve his transfers" (41, 6).
> "Walking quite a lot better" (41, 8).
> "Improve him functionally so he can get back home because that's what he desperately wants to do, transferring and mobilising independently" (41,10-13).

In Period One the physiotherapist said of Jack

> "We are looking at his quite significant weakness on his left side, his balance is quite impaired, his exercise tolerance is really reduced so those are all specific aims that we are trying to work towards" (41, 129-132).

Eventually, each participant had many open codes taken from the ten interviews and conversations.

Whilst the interviews were being carried out and especially between participants (Table 4.10), the open codes were grouped into axial codes, connected in terms of, for example, an aspect of involvement that was derived from the data (Corbin and Strauss, 2008). It was at the axial coding stage that differences between the older people participants became apparent, which can be seen in Appendix Sixteen. The choice of *in vivo* open codes and groupings of these into axial codes is part of the construction of theory made by asking questions of the participants and the data.

Levels of Questions in the Analysis

There were three levels of questions in the analysis designed to elicit meaning and understanding. At the first level there were questions asked of the older people. At the second level there were questions asked of the staff about the older people. Additionally at this level there were recordings of conversations that provided further insight into meaning and understanding. At a third level there were questions asked of the data itself.

At the first level, an interpretation was made about the answers the older people gave to the questions.

The questions are exemplified by:

- Were the questions in the interview understood as intended? What is the significance of any misunderstanding?
- What did the older person mean by the answer?
- What is the significance of this meaning to the aim of the research

Confirming meaning with participants, that is, testing that researcher interpretations of descriptions, analyses and conclusions with those participants who originally supplied the data, has been described as member checking (Guba and Lincoln, 1985). This was discussed earlier in this chapter. A positive member check is a way to maximise the likelihood that the interpretations of the data, by the researcher, are the same as the participant (Doyle, 2007).

> "The truth regarding the phenomenon becomes shared" (p892).

In the way described, member checking is important as it gives the research constructions and conclusions credibility. However, there are others who consider that member checking contravenes the epistemology of interpretive research. It is argued that as interpretation evolves over time, returning research constructions to participants to check understanding is unnecessary and futile (McConnell-Henry et al., 2011).

In this current constructivist research, if there were any doubts about the meaning of answer a participant gave to a question, member checking was carried out by considering the text of past and future interviews and conversations. This checking was done without returning the transcript to the participant and was part of the technique of constant comparison carried out so that useful interpretations were made. An example of need of this type of member checking occurred when Participant Two was being sarcastic about her acceptance of the staff's instruction to let them help her when she would rather have been doing things for herself.

Participant Two said

> "It's as though I'm one of those, you know, getting sprayed with fig leaves and grapes fed to them" (21, 609-612).

The participant was exaggerating the situation to make the point that she was concerned about it. In this case, future and previous interviews were used to determine that she was using sarcasm. Member checking was carried out by collecting more data rather than checking the veracity of data in a similar way to that proposed by Carter (2007).

The second layer of questioning was concerned with the thoughts of the staff about the older people. Although information, given by the participants was accepted for what it was, there were sometimes contradictions. For example, Gordon seemed to overestimate his abilities at home. This understanding arose from interviews with the physiotherapist who assessed him, at home, for rehabilitation. The contradictions were found using the constant comparison technique and again, depending on the issue, future, or past, interviews were used to reconcile the differences.

The third layer of questioning concerned the data itself and is exemplified by

- In what ways were the participants different and similar?

This question is important because by considering the differences in behaviours, in the different areas of rehabilitation work, the meaning of involvement within those areas became understood.
The result of this question, produced axial codes for each participant and for the participants as a group. These were encapsulated within the production of a Cross-Case comparison of the participants, presented at Appendix Sixteen.

The Cross-Case comparison was an internal, qualitative audit, which assisted in the formation of more conceptual codes, then categories that related to all the participants. The cross-case comparison was useful because it facilitated an amalgamation of the data without losing the individual participant approach. The cross-case comparison was pivotal in the initial development of the understanding of the major differences and similarities between the participants, which were later refined.

Descriptions of the data, initially in the Cross-Case comparison (Appendix Sixteen), and later in the tables presented in the construction chapters (chapters six to ten), require a method of summarisation which differentiates the participants according to constructions from the data. This poses a challenge within a research study using a relativist ontology and a constructivist epistemology where the constructions are based on interpretations and there is no claim to define a truth. For example, within constructivism numerical values even at the ordinal level are inappropriate as there is no way of measuring at this level. However, in comparisons of the participants within constructivism it is possible to recognise and communicate differences which need to be described using constructed terms. Within the construction chapters, tables are used to describe the perceived differences between the participants. Within these tables involvement is explained in terms of the perceived strength of the attributes involvement, for example strong, moderate or weak. These terms are constructed qualitative terms, which relate to the participants in this study only and refer to the attributes of individual participants.

Other questions asked of the data were:

- In what way does the current analysis develop the understanding of involvement?
- What does this development do for the progression of the data?
- What are the themes to pursue?

These questions were asked of the data as the analysis progressed and were completed between participants (Table 4.9) and after the end of the data collection period. The questions are important in the logical development of the analysis process towards conceptual categories. In this current research these were the Involvement Attributes and Relationships discussed in Part Three of the thesis.

Finally, the last major question asked of the data was:

- What are the conceptual categories within involvement?

This question was used, as conceptual categories, describing involvement, began to emerge. The importance of individual categories was ranked and sub-ordinate categories were formed.

The open and axial codes and emerging conceptual categories were also used to produce a narrative for each participant, prior to the cross-case comparison. An extract from a narrative of one of the participants is presented in Appendix Five. The narrative reduced the transcripts, kept the cases separate and contained the open and axial codes, as well as my thoughts and interpretations at this stage of the analysis. This technique aligned the categories in the whole research without amalgamating the codes for the individual participants. This was useful, though time consuming, because each narrative became externally relevant to the other narratives. Additionally, the whole analysis process increased my knowledge and understanding of the individual transcripts, codes and participants. In turn, this facilitated the emergence of conceptual categories.

Throughout the analysis, diagrams were used to formulate a picture of the individual older people participants in areas of involvement that were increasingly important. Initial diagrams mapped the progression of the individual participants on to a time grid and considered the participants' internal resources and the compensation, for the participants' impairments provided by the staff of the Intermediate Care unit. Examples of early diagrams about individual participants are presented in Appendix Fifteen.

Part Three

Chapter Five: Constructions

Introduction to the construction chapters

This part of the thesis is presented in six chapters. The first introduces the construction chapters. The other five chapters in Part Three present the conceptual constructions from the research which, together, represents the meaning of involvement for older people in rehabilitation after acute illness.

Throughout the construction chapters various generic terms are used. The term "practitioner" indicates a health care professional, including physiotherapist, nurse, occupational therapist and medical practitioner. The term "support worker" is used to denote those who assist the practitioners in their work and the term "staff" is used to denote the range of people employed in the research setting.

All the names of the participants have been changed, respecting the ethical requirement for the anonymity of participants in research presentations.
In this chapter, each quote has the coded location, related to its position in the interview or conversation transcript. The key to the code was given in chapter four, (Theoretical Framework and Method).

Introduction to Chapter Five, Constructions

In this first chapter, the background of the participants is presented to provide the relevant social and medical history of the participants prior to the need for rehabilitation. Next, an early consideration of the data constructions is provided to facilitate understanding. From a chronological perspective, this early consideration was developed iteratively, during the research and completed at the end of the data collection-analysis period.

Background of the Older People Participants

Participant One: Joe

Joe is a 77 year old ex-miner and foundry worker. He lives with his partner in a two-bedroomed bungalow, which has two seven inch and quite narrow steps at the front door. This is significant as Joe could not lift his feet enough to walk into, or out of, his home, even after rehabilitation.

Joe has rheumatoid arthritis affecting most joints; his left hand is almost completely closed, and his right hand is partially closed and weak, which meant he had difficulty holding a walking frame. In addition to this, Joe has severe gout in his feet which led to difficulties in Period Three of the research and, coupled with a dip in motivation, slowed Joe's rehabilitation progress.

Prior to hospitalisation Joe used to drive but could only walk "12 to14 yards." (1,102) At home, prior to hospitalisation, Joe generally moved round the house with a stick (1, 85) but could sometimes manage without this using the furniture for balance. Joe is unable to clean himself after the toilet when his arthritis is bad and has to ask his partner for help. He finds this a difficult, but acceptable, situation (11, 157-163). Joe could shave himself prior to hospitalisation and although he may not have lost this function in the Intermediate Care unit, the support workers used to shave him until Joe asked if he could shave himself (16, 319-324). Joe could get into his bath at home but could not get out of it without help, so he used the shower. Joe did not need help getting out of bed as he used a rocking motion to build up momentum (11, 110,113).

The largest bedroom of Joe's bungalow has an *ensuite* bathroom. Joe does not sleep in the same room as his partner but sleeps in the smaller bedroom. To wash and shave Joe uses the *ensuite* bathroom in his partner's bedroom whilst she uses the larger family bathroom. After discharge from the Intermediate Care unit, these arrangements remained the same. Joe finds the step into his shower "canny high" (11, 171-174) but has ideas about how the shower step could be reduced (11, 175-182). The sleeping arrangements Joe has with his partner are quite significant to Joe's rehabilitation *post*-discharge, as after rehabilitation Joe required alterations to his *ensuite* bathroom so that it could be used safely. He was waiting for decisions to be made about this and a ramp for his front door, at the last interview in Period Four.

Joe has a history of compliance to health authorities, for example, he took medication for his rheumatoid arthritis (indocid) based on repeat prescriptions for many years without seeing his general practitioner with little understanding of the consequences to his own health.

> "All I got was repeat prescriptions. I never saw the doctor about it" (14 61-62).

This was to be a major factor in the cause of kidney failure which brought him into hospital.

> "Ind... something for my arthritis but they blamed that, er, I had been on them so long, they blamed that for my kidneys. I never bothered the doctors" (11, 527-530).

This was significant as it demonstrates Joe was predisposed to the acceptance of a paternalistic approach to health care.

Joe came into hospital after his partner persuaded him to contact the doctor about his deteriorating feet, which were swelling. Joe's kidneys ceased working "a day or two" after admission and Joe was connected to a dialysis machine (11 11-17) until his kidney function returned. Joe was then confined to bed in hospital for 11 weeks prior to his arrival at the Intermediate Care unit and consequently he could not walk well, or far (11, 28).

Participant Two: Josie

Josie is a 79 year old lady who, prior to hospitalisation Josie lived with her husband at home. Although Josie had carers who came in the morning to make breakfast and in the evening to put her stockings on and prepare her for bed, it was important for Josie to keep as much independence as she could (20, 1122-1124).

At home, Josie was able to make some meals for herself, but her cousin came in at lunch times to make a snack meal for her (20, 4-48). Josie's carers were well organised and, caring for Josie over a long period, would telephone her, before attending to her in the evening, to ask if she wanted a "take away" meal to be brought in (20, 54-56). This was a mark of Josie's organisation skills which she demonstrated in the Intermediate Care unit and, to some extent, later, in the Nursing Home.

Physically Josie could walk to the toilet with a Zimmer frame (26, 26-27) but could not bend down (20, 37-38) and so needed help with her stockings. Josie was careful not to let her cousin do everything for her, wanting to protect her privacy within the family. This was a factor in her choice to move to a Nursing Home later.

> "She's worth her weight in gold. But I wouldn't let her and her daughter shower me. That's how independent I was. I didn't want them to see me in the shower" (20, 854-858).

Josie's stay in the Intermediate Care unit was in two parts. Josie was a research participant for the second admission into the Intermediate Care unit only. The history leading up to this second part provides useful information about Josie's progression and the final outcome of her stay in the Intermediate Care unit.

Josie is a very obese lady and whilst at home developed lymphoedema. Josie's leg changed colour and fluid started to leak into the skin tissue. These leg changes precipitated admission to hospital *via* the Accident and

Emergency department. Whilst in hospital Josie's husband became ill and died. Josie was very sad about this. Shortly after her husband's death, Josie moved from her acute hospital bed to the Intermediate Care unit as she became medically stable and no longer in need of intensive medical support.

At this stage, Josie could walk to the toilet with the aid of a Zimmer frame (26, 26-27), rise from a chair with help and could be moved to a commode. Josie was able to have showers with help (26, 37-42) and attended individual and group physiotherapy sessions.

In the Intermediate Care unit, the main rehabilitation vehicle was physiotherapy. The exercises were rail walking and ball games but, because of a reduction in lung capacity caused by lymphoedema, Josie tired easily. (29, 337-350).

Josie's main goals were to manage without a urinary catheter and mobilise with a Zimmer frame (20, 276-277). During this period of rehabilitation, Josie had a pulmonary embolism and left the Intermediate Care unit to go to the Coronary Care unit, returning as she improved. Josie became a participant in this current research, in the second part of her stay in Intermediate Care, on her return from the Coronary Care unit.

On return from the Coronary Care unit, Josie had a long-term urinary catheter *in situ* (26, 52-53) and could not walk at all (26, 51). Although initial attempts were made at physiotherapy, Josie stopped formal physiotherapy because she was unable to stand. Josie carried on informal physiotherapy, without the guidance of the physiotherapist, using arm weights and doing leg exercises from her bed.

Josie's main relationships were with the nursing and support staff (25, 445-456), which was different from the other research participants whose main relationships were with the physiotherapist and the occupational therapist.

When Josie lay flat, fluid moved to the lungs and abdomen and when she stood, or sat in a chair, the fluid moved to her legs, ankles and feet. Josie moved with difficulty in bed and carers lifted her from the bed with the help of a hoist. However, prior to the research starting, Josie had an accident in the hoist, causing a leg length blood blister which turned into a wound and needed to be dressed daily. From that time on Josie was bedfast (20, 260-267).

> "When I had this accident with my leg I couldn't get up at all. So I'm sort of bedfast all the time now. I can't get out of bed" (20, 234-237).

The accident and resultant leg wound prevented Josie's discharge for many weeks. The presence of lymphoedemic fluid made Josie's leg wound complex and slow healing. Additionally, daily redressing of the wound caused severe pain because of fluid leakage into the dressing. Bed changes, also required daily, were awkward and painful events for Josie.

Prior to joining the research as a participant, Josie had been thinking about whether to go into a Nursing Home, or back to her own home, at the end of her rehabilitation. After the hoist accident, Josie did not want to be hoisted out of bed and this was another key reason for Josie's move into a Nursing Home rather than her own home.

> "No way would I let them come near me with a hoist. Not after this leg" (28, 577-578).

Participant Three: Gordon

Gordon is a man in his early eighties whose profession was driving from which he retired, as a taxi driver, at the age of 76. Gordon lives alone in a bungalow, which has a kitchen/dining room, shower room, two bedrooms and a garden (30, 201-204). Gordon also has a dog as a companion. The bungalow floors are covered with laminate flooring which makes it easy for him to use a Zimmer frame (32, 364-368).

Gordon's daughter is his main carer, backed by his son-in-law who tends the garden (30, 188-189) and makes sure Gordon is safe in the shower (36, 370-387), in case "I fall or owt" (36, 387). Gordon's daughter is able to be his main carer because she lives "At the other end of the street." (30, 58), is able to "pop in when she comes home from work" (30, 60-62) and telephones him frequently (30, 60-62).

Prior to Gordon's admission to the Intermediate Care unit, Gordon's daughter worked hard for her father by shopping (32, 287-290), paying bills (32, 297-

300), doing the housework (32, 322-325; 36, 510-522) washing him (30, 140-142), making sure he had everything he needed (32, 302-305) and that he was safe. Gordon’s daughter also helped him move around the bungalow.

> “If I want to walk anywhere for when I walk to the passage or the toilet she used to help me” (30, 246-248).

Gordon’s daughter also bought food for him and left it for him when she was absent during the day, took him to the social club (on Sundays) (32, 253), picked him up and took him home (32, 255-257). In this way, Gordon’s daughter, compensated for Gordon’s impairments.

Prior to becoming unable to walk, Gordon would get up in the morning on his own (35, 32). He would get himself washed (35, 62) at the sink (35, 71) and was able to make his own breakfast. However, Gordon’s daughter would make his breakfast if he had not had it before she arrived (35,401). Gordon would go to bed at around 10:30pm (35, 405). This is significant because this bed time was changed to an earlier time, 8:30pm, against his wishes, when Gordon left the Intermediate Care unit and a care package was set up.

Gordon tended to sit alone in the kitchen at home all day and had varying opinions of this. Sometimes he found this boring.

> “Well it’s... you get bored sitting in one place all the time” (30, 199)..

Conversely Gordon stated

> “I have a nice garden and I have a nice chair to sit in and I keep just looking outside all the time, but I don’t mind. It’s quite good” (30, 201-204).

Gordon’s medical and functional problems started with a stroke in 2003. The stroke ended his career as a driver and left Gordon with a left arm weakness which, even now, causes some functional problems in terms of washing and dressing. Even so, after the stroke, Gordon managed to go outside to the shops and to his social club (using a mobile scooter) and to walk round the garden at his bungalow. In late 2009, Gordon started to have blackouts and was admitted to hospital. After his return to the bungalow, Gordon became frightened to leave his chair unless someone else, usually Gordon’s daughter, was with him in case he fell (36, 387). Gordon passed the time of day “doing nothing” (30, 97). This reluctance to mobilise led to a reduction in his ability to walk, transfer from chair to commode, get into bed and go to the bathroom. Consequently, the carer role for Gordon’s daughter increased and she moved into the bungalow with her father. The precipitating reason for Gordon’s admission to hospital was that he

> “Literally just went off his legs, that is, his muscle strength decreased” (31, 26) (quote from a physiotherapist).

Gordon’s daughter became exhausted with the extra work. After investigations in hospital, Gordon was admitted to the Intermediate Care unit and joined this research as a participant.

Participant Four: Jack

Jack is an 86 year old retired managing director of an engineering firm with 500 employees (40,321). In his youth he was very active as a sailor and rock climber. This meant that Jack had a keen sense of balance, and confidence in his own abilities. This was significant in how he managed his rehabilitation. Jack now lives with his wife in a

> “Ground floor flat, with two bedrooms, a bathroom, a shower room and it’s got a wet room. It’s got a little patio where I can sit out in decent weather” (40, 353-356).

The ground floor flat is situated within a Victorian building which was recently converted (40, 97) to a high standard and is located near the centre of a small seaside town. This move was planned so that Jack would be able to walk to the shops quickly and easily.

Prior to being admitted to the Intermediate Care unit, Jack had recovered from a stroke (40, 30) and, with help from community physiotherapists and some small alterations to his home recovered to become virtually independent. Jack remained a little weaker than he would have liked to have been. The alterations consisted of positioning of toilet frames and the provision of a shower seat. Jack could walk into town accompanied (42,108) and drove his car for short distances (40,113-117). Unfortunately, soon after his recovery Jack began to “topple over” (40, 34-35) and, following a brain scan (40, 40), had further surgery to remove some clots from his brain (40, 49-53). This surgery left Jack very weak and “completely incapacitated” (40, 61-62). He moved to the Intermediate Care unit “to get a better recovery” (40, 63) and became a participant in this research.

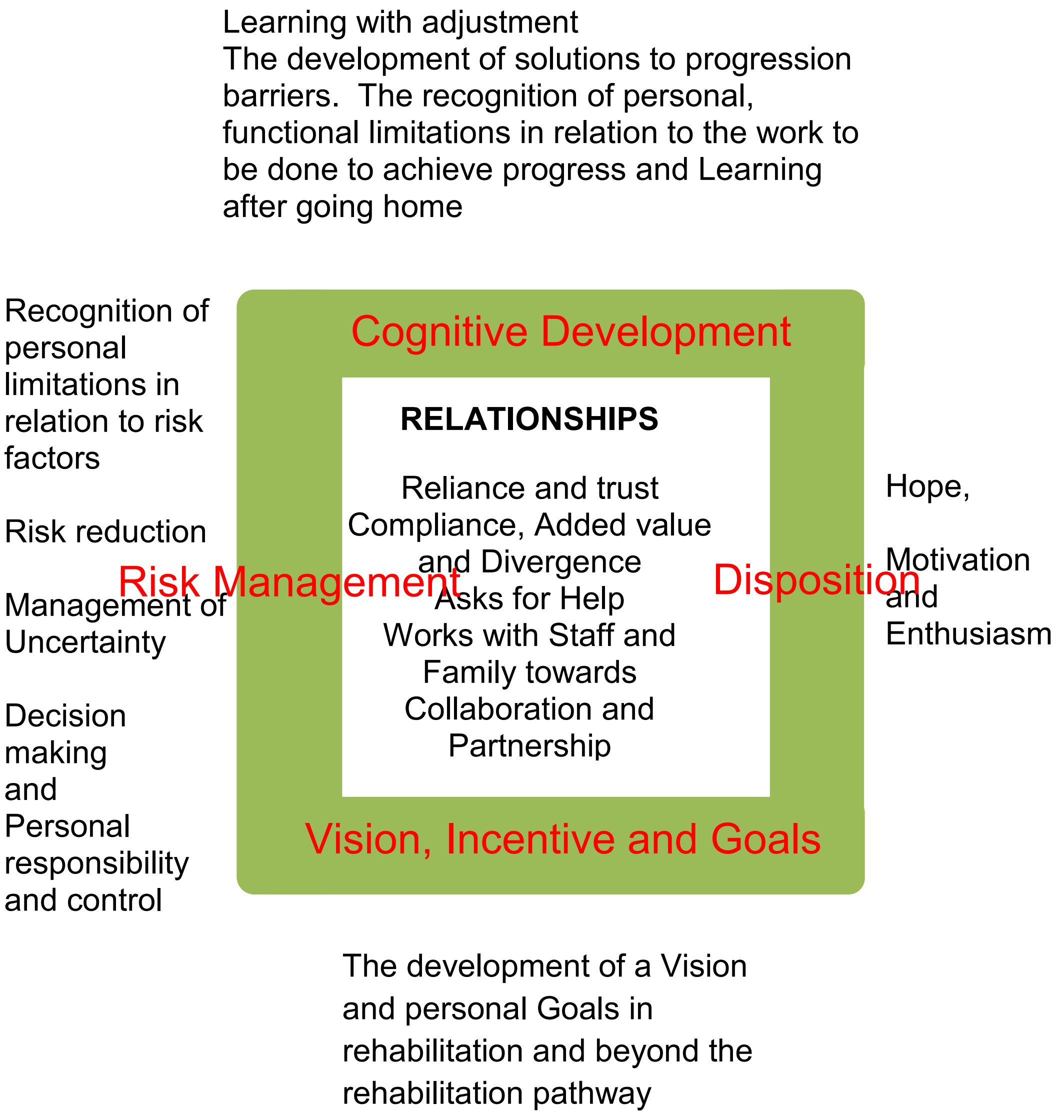
An Early Consideration of the Data Constructions

An early consideration of the data constructions is presented here to assist the reader in the understanding of the constructions chapters. The qualitative research methods, described in chapter four (Theoretical Framework and Method), were applied to the research data produced by the participants, described above. The result of the implementation of these methods and analytic processes was the construction of five conceptual categories with their axial codes. To facilitate an explanation of the association between the categories, a working definition of each category is presented (Table 5.1). A diagram of the conceptual categories with the axial codes is presented in Figure 5.1.

Table 5.1 The Working Definitions of the Five Conceptual Categories, (The Four Involvement Attributes and Relationships) Constructed from the Current Research Data.

	Conceptual Category	**Working Definition**
1.	**Vision Incentive and Goals**	Reasoned, physical and functional aspirations to a life after rehabilitation with reasons and a plan with action to achieve the vision.
2.	**Disposition**	The attitude the participant presented to the rehabilitation situation during the rehabilitation process and comprises of the emotions and feelings that are associated with processes within rehabilitation.
3.	**Cognitive Development**	The process of personal learning demonstrated within the rehabilitation process which embraced adjustment and adaption.
4.	**Risk Management**	The developing attitude towards personal responsibility, choice and decision-making, risk taking and personal control during the rehabilitation process.
5.	**Relationships**	The relationships that participants demonstrate with the staff of the Intermediate Care unit and their family.

Figure 5.1 The Interdependent Involvement Attributes within Relationships in Rehabilitation.



Learning with adjustment
The development of solutions to progression barriers. The recognition of personal, functional limitations in relation to the work to be done to achieve progress and Learning after going home

Recognition of personal limitations in relation to risk factors

Risk reduction

Management of Uncertainty

Decision making and Personal responsibility and control

RELATIONSHIPS

Reliance and trust
Compliance, Added value and Divergence
Asks for Help
Works with Staff and Family towards Collaboration and Partnership

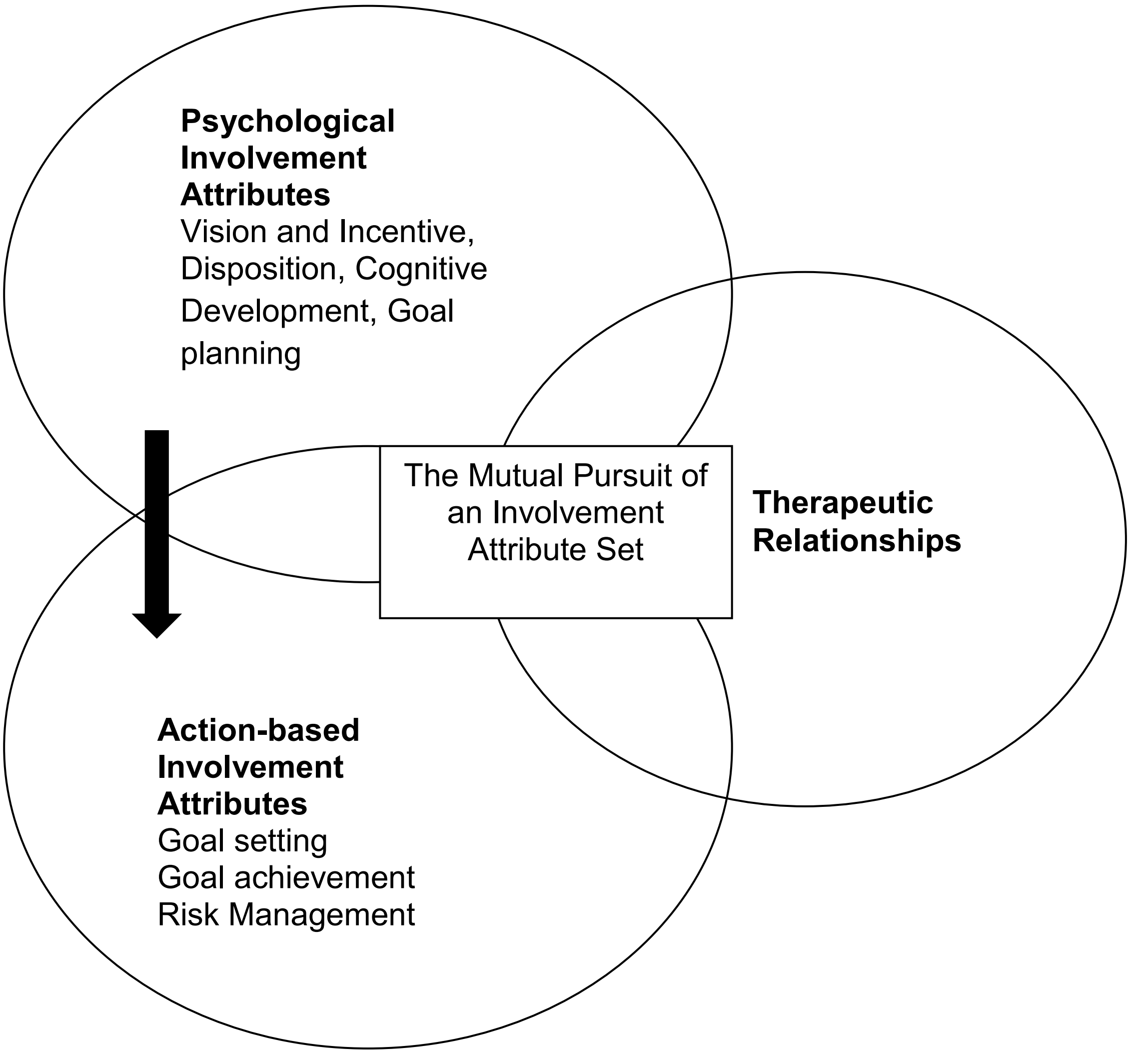
Hope,

Motivation and Enthusiasm

The development of a Vision and personal Goals in rehabilitation and beyond the rehabilitation pathway

Four of the conceptual categories represent an interdependent Involvement Attribute set which, in this current research, is expressed through the fifth conceptual category, relationships with the staff of the Intermediate Care unit which facilitates the mutual pursuit of the Involvement Attribute set. Involvement operates through this Involvement Attribute set which consists of two interdependent groups of Involvement Attributes. These groups are the psychologically-based Involvement Attributes and the action-based Involvement Attributes. The psychologically-based Involvement Attributes are: the possession of a Vision, Incentive and Goal planning, a positive Disposition towards motivation in terms of hope motivation and enthusiasm and a propensity for Cognitive Development. The action-based group of Involvement Attributes are: Risk Management and Goal setting and Goal Achievement. Goals therefore span both Involvement Attribute groups. Additionally, the action-based Involvement Attribute group are products of the psychologically-based Involvement Attribute group (Figure 5.2). To be maximally involved a person has to have an Involvement Attribute set which is strong, balanced and incorporates an alignment between the psychological and action-based groups.

Figure 5.2 The Involvement Attributes and their interrelationships



In the construction chapters, the individual Involvement Attributes have been separated facilitate the detailed analysis. Although this separation facilitates discussion, it is not intended to underplay the interdependency of the Involvement Attributes which is demonstrated on many occasions in the construction chapters. For example, when there is evidence of a participant adjusting their ideas (Cognitive Development) during a conversation with practitioners (Relationships) the attitude to that adjustment (Disposition) may lead to different plans for action (Risk Management) strategies. Additionally, the interdependency is required to explain Involvement this explanation is provided in the conclusion to the Construction chapters.

Chapter Six: Vision, Incentive and Goals

Introduction

The participants identified visions that pictured a life after rehabilitation. For those who were most involved, the visions were associated with a level of non-acceptance of the *status quo* and incentives for achieving the vision. Within the Involvement Attributes, the “Vision” represents the aim of rehabilitation, and the “Incentive” the reason for the aim. The “Vision and Incentive” was expressed in different ways by different people and waxed and waned during the rehabilitation period. Additionally, there were opportunities for the Vision and Incentive to develop further beyond the rehabilitation stay, when the participant was at home. Within the Theory of Involvement the Vision and Incentive occurs within the psychologically-based Involvement Attributes.

Closely associated with the development of a Vision and Incentive is the formation of goals. The planning, setting and achievement of these, driven by a non-acceptance of the *status quo,* was the active process through which the Vision was attained. Four types of goals and their significance are discussed both within the rehabilitation stay and after discharge. The goals occur split between the psychologically-based and action-based Involvement Attributes which is discussed in chapters ten (Relationships) and eleven (Study Discussion).

Initial Visions and Incentives

The participants demonstrated two different initial positions related to their Vision and Incentive. Taking the first position, two of the participants had an initial strong Vision and Incentive that they worked towards and were variably successful. This process was named vision confirmation (Diagram 6.1). Those participants who were most concerned with a complete restoration of their abilities took this position and demonstrated both positive and negative Visions and Incentives.

Positive Visions and Incentives included

> “[To] Get home to my family ... which is a natural thing after being away for 15 weeks like” (16, 561-562).

Negative Visions and Incentives included

> “Oh, I think getting home and getting myself mobile so that I don’t become a burden. I have no ambition to be in an old people’s home playing bingo and singing hallelujah, just to get back to normal” (46, 602-606).

Table 6.1 The Interplay between Goals and Vision Development and Confirmation

VISION DEVELOPMENT	GOAL ACHIEVEMENT AND DISCHARGE	VISION DEVELOPMENT	POTENTIAL GOAL ACHIEVEMENT
GOAL PLANNING SETTING AND ACHIEVEMENT AT FOUR LEVELS Pre-Functional Functional Activity-Based Social Participation			
VISION CONFIRMATION		VISION CONFIRMATION	

Time →

The second position was associated with a weaker, initial Vision and Incentive that was developed, iteratively during the rehabilitation, and was called Vision Development (Table 6.1). Josie exemplified this position. Josie was going to go home from the Intermediate Care unit for a trial but, through a process of discussion with the staff and reflexion, she came to understand that she would have more difficulties, be isolated and have wasted expenditure if she stayed at home rather than move into a Nursing Home. The home trial became unnecessary.

> “I intended going home first and seeing how things worked out. But the longer I’ve stayed here and see the way I am, I know it’s a waste of time going home. Because I’m far better just go to the Nursing Home where I’m being looked after because by the time I pay this one and that one and the other one, it’s going to be costing me nearly as much money. And after all, it’s my quality of life I’ve got to think about” (20. 290-303).

Gordon also had an initial weak Vision and Incentive, but this did not develop. During a physiotherapy assessment, prior to going into the Intermediate Care unit, Gordon was preparing to go into care and was not concerned about this. His physiotherapist stated

> "[Gordon] didn't seem that bothered that he was going into care" (38, 202).

In Period One, Gordon's "Vision and Incentive" strengthened a little and he wanted to stay at home.

> "Oh I'd like to stop at home" (32,521).

However, the Incentive behind his vision remained vague. In Period Two, when asked what was going to be good about going home, Gordon said

> "Oh I just like to go home that's all: better surroundings, more to see" (35,10-18).

Gordon represented the weakest Vision and Incentive Attribute of all the participants, which reduced his involvement.

The possession of a Vision and Incentive is a psychological process that is demonstrated through the planning, setting and achievement of goals. Differences in the interplay between the Vision and Incentive and the process of goal achievement, over the period of rehabilitation and after discharge, further demonstrated stronger or weaker involvement in the rehabilitative process (Table 6.2).

Table 6.2 The Development of the Vision, Incentive and Goals by the Participants

Period	Involvement Attribute	Participants			
		Joe	**Josie**	**Gordon**	**Jack**
One	**Vision and Incentive**	Strong	Not formed	Not formed	Strong
	Goals	Mainly Social Participation Some activity No pre-functional	Not formed	Not formed	Pre-Functional, Functional, Activity-Based and Social-Participation
Two	**Vision and Incentive**	Strong	Strong and unattainable	Weak	Strong
	Goals	Mainly Social Participation some activity-based,	Some covert and unattainable. These were Activity-Based and Social Participation	Functional and Activity-Based	Pre-Functional, Functional, Activity-Based and Social-Participation
Three	**Vision and incentive**	Strong	Strong	Weak	Very strong
	Goals	Mainly social participation Some Activity-based **Missing** pre-Functional Goals	All personally owned. Some covert and unattainable These were Activity-based and Social Participation **Missing** Pre-Functional and Functional Goals	Functional and Activity-based **Missing** Pre-Functional and Social Participation Goals	Pre-Functional, Activity-based and Social-Participation

(This table is continued on the next page)

Table 6.2 The Development of the Vision, Incentive and Goals by the Participants (Continued…)

Period	**Involvement Attribute**	**Participants**			
		Joe	**Josie**	**Gordon**	**Jack**
Four	**Vision and Incentive**	New vision forming based on Activities and Social Participation	Despair at the unattainable “old” vision	Unconcerned no particular vision	Moving forward with the same vision
	Goals	New, but no way of achieving these, unaided	Reluctant acceptance that the goals will not be achieved	None	Continuing on his own pathway
Wanting to move forward in rehabilitation		Yes	Yes, but unable to find a way forward	No	Yes
Level of Involvement		Apparently Strong	Strong socially Weaker physically due to misalignment	Weak	Strong
Balance of the Involvement Attributes		Some imbalance	Weak	Strong	Slight imbalance

Different Types of Goals

There were four levels of goals demonstrated in the current research. The first was pre-functional. This was demonstrated by Jack when he stated that he wanted to get his strength back.

> “Yes well sometimes I lie on the bed cos I can do exercises to strengthen my thighs” (42,13-14).

A second level was functional, for example Joe wanted to

> “Get the use of my legs back” (11, 237-238).

A third level of goal was activity-based. For example, Jack’s goals included

> “To get completely independent walking, showering and looking after myself” (40, 206-07).

The fourth level, social participation, was demonstrated by Jack who explained what independent walking would allow him to do.

> "Go to the shops, quite normal" (40,481-482).

This difference in the level of the goal demonstrates different levels of thinking as well as achievement which had an effect on the level of involvement. Older people who do not have goals at all four levels seem to be less involved than those who do demonstrate goals at four levels.
For example, Gordon, whose involvement was weaker, had no pre-functional goals. However, Gordon did have functional goals. In Period One, Gordon's goal was

> "For to try and get us walking on my legs" (30,41).

In Period Two, this moved on to an activity-based goal, but not to the level of Social Participation

> "Using the Zimmer frame to get from the kitchen to the bedroom" (32, 456).

Joe, whose involvement was reliant on the staff, had activity-based goals and social participation goals. Joe wanted to be able to walk and go home, to be with his partner. However, Joe did not have his own pre-functional goals.

> "How can I put it I'm not gened up [I do not know enough] how much they want you to do each day ya na I'm just going off what they say" (12, 66-69).

The achievement of Josie's "Vision and Incentive" through the development and achievement of goals demonstrates how complex goal achievement can become. Reluctantly accepting that she had to move from the Intermediate

Care unit in Period Two, Josie created some unattainable, activity-based and social participation goals centred on a move to a Nursing Home. Josie's activity-based goals included

> "To be able to get out of bed" (26, 14).
> "Get on the Zimmer to go to the toilet" 26, 58-61).

Josie's social participation goals were concerned with walking, going to the toilet and engaging in the social life of the Nursing Home

> "Most important things in my life now? It's just being able to get settled in the Home and hoping that I can get up and walk with my Zimmer. And I've got a bathroom. I don't know what the bathroom includes, mind, but at least the toilet is there. So just to be able to get into the Home, even being able to walk with my Zimmer just to the bathroom is going to be a great thing for me. Being able to go to the toilet properly. Then, as I say, if I can get a round on my Zimmer… I've got two little buggies – you know the ones… Little scooter types?"
> "Well if I can get around in the home on a little one, I would be able to get down and join in with things. Because, I mean, they have like little pea and pie suppers and different things like that. Well, I'll be able to going in all of them, you see" (21 402-406).

Josie was not involved in a physical rehabilitation regime like the other participants as discussed later in this chapter. Josie developed no pre-functional or functional goals that she might have taken control of herself. Additionally, the social participation-based goals, which would require pre-functional and functional goals, were not formally discussed with the staff of the Intermediate Care unit. This represents a misalignment between the psychological group of Involvement Attributes and the action-based group of Involvement Attributes.

Achievement of the goals, at different levels, also seems to be hierarchical in that, without a concentration on pre-functional and functional goals, activity-based and social participation goals become more difficult. Josie, Gordon and Joe did not have pre-functional goals and so missed out on important involvement opportunities in the process of rehabilitation, associated with accomplishment. This is discussed further in chapter eleven, Study Discussion.

The Production and Achievement of Goals Beyond the Rehabilitation Pathway

Rehabilitation was not complete at the end of the rehabilitation stay. There were opportunities for each participant to continue goal planning, setting and achievement *post*-discharge. (Table 6.2). However, the structures within which these goals would be achieved were different after discharge. Each participant had different structures, three participants moved back to their home and one moved into a Nursing Home. The rehabilitation behaviours and management, within these new structures, demonstrates the level of involvement as a product of the rehabilitation in the Intermediate Care unit and the discharge environment.

The strongest involvement was demonstrated where the goals spanned all four levels *post*-discharge **(**Table 6.2) and rehabilitation was able to be continued within the available facilities without the continual care and direction of rehabilitation staff. This position was exemplified by Jack. Jack did not need the practitioners, he wanted to progress on his own

> "To prevent falls, you don't need to grab something. Sometimes, just a finger- tip is enough to give you the balance you need" (48, 462-464).

Jack worked with pre-functional, functional and activity-based and social participation goals. This demonstrated stronger involvement. Jack said

> "I think it will be tough at the beginning you know showering and dressing myself but I am sure if I try, I have the will, it will be ok and easier as the days go on" (46, 497-500).

Jack's home structures were also facilitative. Jack said

> "I think the fact that I can get home I have got enough space and availability of movement in my flat to be able to continue every day with therapy walking and stretching" (46, 383-388).

The position described above represents strong involvement and provides opportunities for success. There are many other situations, which are not optimal, based on the emphasis older people placed on different levels of goals and the facilities available that helped or goal achievement. For example, Joe did not develop pre-functional goals but did have functional, activity-based and social participation goals (Table 6.2).

> "I want to get out and sit on the wall outside you know just for a bit of fresh air" (19, 238-239).

> "I hope within three months to be able to get round unaided without the Zimmer if I can like you know?" (19, 461-463)

> "Well I as I say I am housebound but, erm, once I get that chair [rising chair] I'll get in the car just up and down the drive. If I can't manage [to drive] I'll just have to sell it [the car] and maybe get one of these electric, erm, chairs where you can go around by yourself like" (19,364-369).

Joe's home structures hampered his involvement. Joe put his hopes on external resources, his promised home alterations, a ramp and a rising chair. It seemed that Joe did not want to take charge of the process of rehabilitation at the pre-functional, functional or activity-based level and this weakened his involvement.

After discharge, Joe was left perplexed because although he had done what he was told to do in the Intermediate Care unit, and had achieved his goal of going home, he could not achieve his activity-based and social participation goals. He had not developed his own pre-functional and did not have his own way of achieving his functional goals. Joe still required direction from an external source, the practitioners.

> **“So did you say to them could I stay a bit longer?”**
>
> “Oh no. I was 16 weeks, I was glad to get out. That never crossed my mind at the time until I got home and then I realised, maybe I should have, erm, be better if I stop here until all the alterations are done, but I was back glad to get out” (19, 225-243).

In rehabilitation terms, Gordon represents involvement at a low level. Gordon had no strong personal goals, at any of the levels. Although his home was suitable, Gordon did not develop a process of goal achievement. Gordon remained unconcerned about the changes that had been brought about and, though he was pleased with his functional improvements, had no intention to improve further.

A practitioner asked Gordon if

> “Going home would be a hard struggle? Or do you think it’s just going back the way it was” (33, 171-173.

Gordon replied

> “Just the same” (33, 174).

When Josie began to understand that her social-participation and activity-based goals were unattainable, *post*-discharge, she became less involved and despondent.

> "I say every morning when I wake up I think, oh my God I'm here still" (19, 120-124).
>
> "I've kept saying to our [name] mind, If I die, don't worry about it because I'm not frightened to die, but I haven't said to her I pray every night that I don't wake up the next morning" (19, 453-456).

The development of Vision, Incentive and Goals in each of the participants is summarised in Table 6.2.

Conclusion

The participants demonstrated different levels of involvement based on their Vision, Incentive and Goals. Those with the strongest involvement had a strong and consistent Vision and Incentive and Goals. The goals appeared hierarchical over four levels. Starting at the lowest level, these were pre-functional, functional, activity-based and social participation goals. Those with the strongest involvement developed all four types of goal which facilitated a personal interest in the rehabilitation process and personal accomplishment. Those who were less involved had at least one of these levels missing. One participant had no strong personal goals and a very low level of involvement (Table 6.2). Another participant demonstrated misalignment between the psychologically-based and action-based Involvement Attributes.

Chapter Seven: Disposition

Introduction

This chapter is concerned with the attitudes of the participants towards their rehabilitation. These attitudes were demonstrated by the way the participants thought and behaved with their practitioners during their progression through the Intermediate Care unit. The chapter discusses Disposition in terms of the axial codes within it which are: Hope, Motivation, and Enthusiasm. All the Disposition group of Involvement Attributes occur within the psychologically-based Involvement Attributes

Hope

Neither the older people nor the staff could know how far rehabilitation would be able to be taken, *a priori,* nor what external resources, in the form of home alterations or further help, would be needed after rehabilitation. This would only become known *a posteriori* as the older people moved through the rehabilitation pathway. Those older people who had goals at the start of their rehabilitation hoped these would be achieved. Others developed, or failed to develop, hope related to their goals as the rehabilitation progressed.

The participants demonstrated a range of hope states. For example, Joe had a blind hope (defined in Table 7.1) that eventually left him perplexed, Josie's hopes exceeded what she could achieve physically and were probably used, cognitively, to keep her spirits up. Gordon demonstrated little hope, which reduced his involvement, and Jack’s hope was useful because it helped him to achieve his personal goals.

Overall, significant hope was demonstrated within the goals of the participants. For example, hope was a key element in one of Joe’s social-participation goals bound up with his fear, a negative hope about the need for a wheelchair. Joe also ruled out “walking any distance” which demonstrates a weaker hope in terms of social participation. This may mean he was focussed on activity-based goals, but in Joe’s case, given his other behaviours, discussed in the background and other construction chapters, this demonstrates that he had weaker hopes. Joe said

> “Well I would like to think I could drive again like but at the minute I have got my doubts you know. As far as walking for buses, although I have got a pass I think it would be out of the question walking any distance and I divent [don’t] want the onus of having to get a wheel chair and having to be wheeled around you know” (11,142-144).

Joe’s blind hope state was based on trust in the rehabilitation staff rather than on his personal accomplishment. Although this type of blind hope might be expected at the beginning of rehabilitation, when the participants were first learning about themselves and their impairments, it did not seem to leave Joe who said

> “Well I try to help them as much as I can ya kna [you know]” (11,354-357).

Josie used unchallenged hopes of independence to keep herself enthusiastic. Even though she was bedfast Josie was

> “Hoping that I can get up and walk with my Zimmer” (20, 369-370)

> “But whether I ever will or not, I don’t know. But there again, I might. I’m keep thinking, well, I might. The summer is coming on. If I get to the Nursing Home and I get on my buggy, I can go over to the shops on my buggy. I can meet our [Name] and them, you know, in a pub and have a lunch. So I’m just hoping” (20, 906-914).

This position changed in Period Four, in the Nursing Home, and Josie’s hope for the future began to falter.

Gordon’s lack of focus about his functional ability showed that his hopes for physical and functional improvement were not very challenging and he was less involved than the other participants. However, even though Gordon’s goals were weak they were more attainable than those of Josie.

Another type of hope was more useful. Jack believed his improvement lay in pre-functional goals, for example, increasing his strength, which he hoped to regain. Jack’s solutions were personally-owned demonstrating stronger involvement. In Periods Three and Four respectively, Jack said

> “I have increased my diet and tried to get another stone on me. I lost about two stones” (46, 167-169).
>
> “I need to get weight on to get strength” (49, 173).

The development of the different types of hope in each of the participants is summarised in *Table 7.1.* The constructions indicate that to be purposefully involved, hope is necessary but to be most useful, hope has to be focussed on personally owned, achievable and relate to pre-functional and functional goals as well as activity-based and social-participation goals.

Table 7.1 A Description of the Participants' Types of Hope

	Joe	**Josie**	**Gordon**	**Jack**
Type of hope	Blind hope (that is, hope without due consideration of the process required	Unreasonable hope (that is, hope for unattainable goals	No particular hope	Useful hope (that is, hope linked to achievable goals
. **Outcome**	Perplexed	Beginning to despair	At risk of deterioration	At risk of falling

Motivation and Enthusiasm

In this research, motivation was taken to be the drive that the individual had to succeed, and enthusiasm was the demonstration of the direction of that drive. For those participants most involved in their rehabilitation, their motivation was a drive to make a change in their current position based on non-acceptance of the *status quo*, as discussed in chapter six, Vision Incentive and Goals. The meaning of involvement includes enthusiasm concerned with the way participants engaged in the *process* of rehabilitation through active participation and the use of resources. The participants differed in the way they took part and used resources in the rehabilitation process, demonstrating different levels of involvement.

Three of the participants demonstrated clear motivation drives (Table 7.2). This was noted as they recognised their progress. Joe was able to recognise the progress he had made towards reaching his goal in Period

Two.

> “One time I had to ring during the night. If I slid down the bed regular I ring them to come to get me back up. Now I find I can get up the bed myself” (14, 36-38).

Jack was able to recognise his progress but he was not satisfied with becoming functionally better. Jack knew he had to make more progress through the development of his stamina, a pre-functional goal (Table 7.2).

Josie was unable to make progress in the same way as the three other participants. Josie concentrated on making social progress out of the Intermediate Care unit. In terms of her physical ability, Josie’s social participation goals were misaligned with her physical goals. Josie wanted to have a social life in the nursing home which required her to be able to get out of bed. Unfortunately Josie was bedfast with no prospect of this changing (Table 7.2).

Although Gordon recognised that improvements had been made, he did not relate these to any goals about improvement. For example, Gordon stated that physiotherapy made him “feel good” (33,120-122). Therefore Gordon’s level of involvement relating to motivation was weaker than that of Joe (Table 7.2).

Table 7.2 The Participants' Motivation and Enthusiasm Relating to the Recognition of Progress

Area of work	Joe	Josie	Gordon	Jack
Motivation. Wants to succeed	Yes, relies on staff for direction	Yes in terms of socially-based goals yes in terms of physically-based goals.	No.	Yes, works on his own pathway
Enthusiasm Takes opportunities for informal functional progression	Yes under direction	Yes (socially-based goals No in physically-based goals.	No	Yes of his own volition
Recognition of functional or other progress	Yes	Yes (social participation) No (Physical improvement	No	Yes

Each of these three participants demonstrated different enthusiasms for their work and different levels of Involvement (Table 7.3). Joe demonstrated enthusiasm through hard work and eagerness at the bidding of the practitioner. Joe worked hard, especially in Periods One and Two, as if he was helping the practitioners rather than the practitioners helping him. In this way, Joe was working on the physiotherapist's rehabilitation pathway and not his own pathway. Whilst Joe was improving and the physiotherapists were working with him, Joe's enthusiasm was strong. The physiotherapist said

> "He is so keen and so motivated erm..., and often the problem with that is that he can't see how much he has improved 'cos he has improved a tremendous amount because he is still wanting to move forward. That's a good thing you know, to see where he wants to be" (15, 56-65).

However, in Period Three, Joe revealed his dependence on the practitioners as his enthusiasm began to wane when he found the rehabilitation harder.

Unexpected physical setbacks reduced his motivation and enthusiasm, which was compensated for by the physiotherapists. Joe's enthusiasm waned because he was not concentrating on the process of rehabilitation and his own goals. The physiotherapist said

> "I can understand how his motivation can dip because, because he has had such a lot of physical problems as well [for example foot swelling and pain]. I am trying to encourage him to exercise and, erm, in his own time not just in his physio. session" (17,161-166).

Joe assumed that the physiotherapist's goal was to work to make him independent so that he could return to an independent life. However, the physiotherapist's goal was to work with Joe towards becoming as independent as possible so that when he went home, the care that Joe might need at home would be minimised. At the end of his rehabilitation, Joe was discharged home safe, but not independent and his home was still in need of home alterations.

> "Yeah, he was really independent [before hospitalisation] so ultimately that is what you always hope to achieve but we... but realistically we mightn't achieve that but, or what I will do with Joe I feel that one of our... our biggest aim really is to get him home, safely" (15, 196-203).

This enthusiasm, at the bidding of the practitioners made Joe's involvement apparently strong but in real terms this was weaker.

Gordon, who was not enthusiastic and participated in his physiotherapy by request. Unlike Joe, Gordon was not eager to work with the practitioners.

> "They know how far they can go like" (33, 134).
> "I don't ask them nowt [nothing] I just let them get on with it. (33,158).

In this way Gordon was not very involved in the physiotherapy.

Jack was far more enthusiastic at the beginning of his rehabilitation stay and demonstrated personal ownership with his enthusiasm.

> “I don’t think there’s anything else here [other than physiotherapy] if they get me moving I’ll try to do the rest myself” (40, 347-348).

Jack worked hard, like Joe, but differed because he was working for himself, not the physiotherapists.

The physiotherapist said of Jack

> “I think he is pushing himself quite a bit which is good but I don’t think he appreciates he was really poorly just a couple of weeks ago” (41, 92-95).

Jack said

> “I’ve got to push myself” (43, 319).
> “Everything is an effort” (43, 323).

These three participants demonstrated different types of enthusiasm which led to different levels of involvement. Joe was enthusiastic about joining in the process provided for him, Jack used the process provided for him and Gordon went along with the process provided for him (Table 7.3).

Table 7.3 A Description of the Way the Participants Directed their Enthusiasm in the Intermediate Care unit, Related to Levels of Involvement and Outcomes

Time	**Joe**	**Josie**	**Gordon**	**Jack**
Period One	Motivated to succeed, Did what he was asked to do enthusiastically	Motivated to succeed socially. Enthusiasm partially dependent on mood the staff and her family	Personally not motivated and had weak enthusiasm Participating by request only	Motivated to succeed. Enthusiastic to learn about himself
Period Two	Motivated to succeed. Did what he was asked to do enthusiastically Some evidence of personal ownership	Motivated to succeed socially. Enthusiasm partially dependent on mood, the staff and her family	Participating by request only	Motivated to succeed Participating through personal ownership
Period Three	Motivated to succeed Enthusiasm waning Participating by request only	Motivated to succeed socially. Enthusiasm partially dependent on mood, the staff and her family	Participating by request only	Motivated to succeed Participating through personal ownership
Cognitive Learning	Weak	Strong socially	Very weak	Strong

(This table is continued on the next page)

Table 7.3 A Description of the Way the Participants Directed their Enthusiasm in the Intermediate Care unit, Related to Levels of Involvement and Outcomes (Continued…)

Time	**Joe**	**Josie**	**Gordon**	**Jack**
Outcome at Period Four	Looking for continued support from the practitioners and external motivation	Motivation moderate Enthusiasm ranged at different times from strong to weak. Coming to terms with misalignment	Motivation weak. Enthusiasm weak. Participating by request deferring to his daughter and his carers after discharge.	Motivation high Participating through personal ownership supported by his wife and family
Level of Involvement	Strong in Periods One and Two	Strong at times	Very Weak	Very Strong

Josie was very similar to Jack, except her enthusiasm was directed at making herself comfortable in the unit and finding a way forward for herself. Josie demonstrated that enthusiasm may not necessarily be associated with functional improvement. Josie's enthusiasm was directed towards social success rather than her functional success and, like Joe, was somewhat reliant on the practitioners and family to achieve her goals. Josie was almost totally reliant physically and was sometimes psychologically reliant dependent on her mood. Josie said

> "In myself some days, uh-huh. But then other days I have my depressed, moody, tired days like yesterday. I couldn't have cared if I had anybody here or not because I just really couldn't be bothered. And I felt sleepy all day. But the likes of today, up until now, I feel alright", (28,161-168).

Overall, Josie had enthusiasm for the move to the Nursing Home and enthusiasm for social participation that was not discussed with the staff and could not come to fruition.

Table 7.3 describes how the participants reacted to their rehabilitation work. However, it does not explain who the enthusiasm was aimed at. This is important as it provides further evidence of the different levels of involvement.

In addition to enthusiasm related to the work within rehabilitation, three further types of enthusiasm were demonstrated by the participants, which further reflected their goals, hopes, and the relationships they developed with the practitioners. These were enthusiasm for pleasing the staff, enthusiasm for pleasing self and enthusiasm about the relationships with the staff.

Joe demonstrated enthusiasm concerned with pleasing the physiotherapists.

> "If I'm going for physio I just say right I'm ready for physio. I don't argue with them because they know their job." (11, 298-300).

Jack also felt that he needed to please the practitioners, as exemplified by the way the occupational therapist discussed their conversations towards the end of Jack's rehabilitation stay.

> "I think he slightly feels, I think he is slightly worried that I might say you can't go home or something and I think he is slightly intimidated by people in uniforms maybe" (47, 380-383).
>
> "[Jack would] try and make sure that he was saying what I wanted to hear" (47, 419-420) "so he could get out of here" (47, 432).

This type of pleasing the staff was different to that of Joe. Jack was trying to ensure that external resources, in this case the occupational therapist, did not divert him from his goals. In Joe's case pleasing the staff was from a trust in them to achieve his goals.

Jack was also enthusiastic about pleasing himself. This operated throughout his rehabilitation, and was demonstrated, for example, when he knew that he had to build up his strength in order to succeed. Conversely, Gordon did not seem to have enthusiasm for rehabilitation. He was a man of few words, who did not seem to join in the socially-based spirit of rehabilitation and successes. It was as if the rehabilitation was completely separate from him. When asked if there was anything "we can improve on" he answered

> "No not really. Just the physio has done me a lot of good" (36, 441-445).
> "It got me to move my legs" (36, 452).

Josie demonstrated the third type of enthusiasm relating to the relationships that she built up and needed.

> **"**I mean, there's only the staff and my family that I got to talk to, you know what I mean?" (29, 440-442).

Josie enjoyed

> "Being so friendly with everybody and everybody looking after me so well even the doctors."

This type of friendship relationship was not developed by Joe, Gordon or Jack and could have been a feature of the type and level of physical reliance that Josie alone experienced.

The direction of the three types of enthusiasm are summarised in Table 7.4.

Table 7.4 A Description of Three Types of Enthusiasm, and a lack of enthusiasm, that Demonstrate Levels of Involvement Related to Outcomes

Research Period	**Joe**	**Josie**	**Gordon**	**Jack**
Period One	Pleasing staff	Building friendships	Not enthusiastic	Pleasing self
Period Two	Pleasing staff	Mixed enthusiasm control of the environment, friendships hampered by mood	Not enthusiastic	Pleasing self
Period Three	Pleasing staff	Mixed enthusiasm control of the environment, friendships hampered by mood	Not enthusiastic	Pleasing self and pleasing practitioners
Outcome at the End of the Research	Unsure what to do, facing new challenges	Mixed enthusiasm control of the environment, friendships hampered by mood	Remained unenthusiastic Little interest in functional progression	New challenges with the support offered to him

Conclusion

The Disposition category, (Involvement Attribute) was supported by three axial codes *viz*, hope, motivation and enthusiasm. Each of the participants demonstrated different types of hope, Blind hope, Unreasonable Hope, No Particular Hope and Useful Hope. Demonstrations of Useful Hope, associated with personal growth towards accomplishment demonstrate stronger involvement whilst other types of hope present barriers to involvement. For example Blind hope was associated with too much dependence on others, Unreasonable hope was associated with unreasonable goals and no particular hope was concerned with a lack of interest. Motivation and enthusiasm were considered to be closely associated as motivation was harnessed by enthusiasm for particular aspects of rehabilitation. Enthusiasm for pleasing self was an important part of involvement and where there was enthusiasm, for example for pleasing others, this made involvement was weaker. Where motivation was thought to be weak enthusiasm was also weak. Motivation and enthusiasm were also associated with building friendships, in this case as ways of organising assistance. In this way building friendships represents a social component to rehabilitation.

Chapter Eight: Cognitive Development

Introduction

This chapter is concerned with the participants' learning processes, about themselves and their environment during rehabilitation. Cognitive Development operates within the psychologically-based group of Involvement Attributes. The category is discussed in terms of the axial codes within it which are: Learning and Adjustment to Changing Levels of Dependency, The Recognition of Impairments in Relation to the Work Done to Attain Functional Improvement, Seeking Personal Solutions to Progression Barriers and Learning after Going Home.

Learning and Adjustment to Changing Levels of Dependency

Operant and Cognitive Learning

Operant learning in rehabilitation (Wood and Alderman, 2011) is learning directed, based on reward and punishment for narrow purposes such as learning how to do exercises at the request of a physiotherapist. Participants learning in an operant mode learned how to respond to instruction and remember instructions based on external sources of reward. There is an element of operant learning in the development of all new skills when these are directed externally, for example, learning new exercises from a physiotherapist. From an operant perspective, some of the behaviours exhibited by the participants may be pre-determined, solely based on past experiences, which dictate the responses of the participant. However, consideration of an operant learning explanation for involvement alone would negate the part played by those most involved in their rehabilitation in terms of personal, innovative and reflective forethought which led to actions determined by the individual rather than the practitioners. From the constructions in this research, involvement in rehabilitation demands more than operant learning and suggests that involvement requires a level of prospective, cognitive learning.

Types of Cognitive Learning

Two types of adult cognitive learning are recognised: Informational (Mezirow (2000) and Transformational (Mezirow, 1978). There were opportunities for both types of cognitive learning as the participants came to understand themselves and their impairments through rehabilitation. Examples of opportunities for transformational learning included the preparation for transition into a Nursing Home (Josie) and the acceptance of a reduction in physical capabilities (Joe). Opportunities for informational learning were entrenched in the rehabilitation process as the participants learned about themselves through the experience of rehabilitation and reflexion, directed by the physiotherapists and occupational therapists. All the participants were able to learn in an operant mode, and two clearly demonstrated cognitive informational learning. It is difficult to construct the difference between transformational and informational cognitive learning strategies from the data in this current research because of the short duration of the data collection period and perhaps the default paternalistic approach to rehabilitation of the staff. In future research, under a critical theory epistemology, it may be possible to direct attention to distinguish between the two types.

The ability to learn and adjust is an important part of involvement in rehabilitation. In order to achieve their vision of change, whatever this was, people in rehabilitation need to take opportunities to learn about the context, their functional impairments, the way they are managed and their role in rehabilitation. In the cases of Joe, Gordon and Jack, their prime concern was improvement and going home. In Josie's case her learning concentrated on how her care should be managed. The different approaches meant that Josie had more access to the nurses, care staff and medical staff than the other three participants who worked with the physiotherapists and occupational therapists.

There are many barriers to learning, such as capacity and disposition, but involvement appears to be weakened where cognitive learning is not maximised (Table 8.1). The participants demonstrated a variety of reactions to the opportunities made available to them to learn. There were examples of failure to learn both operantly and cognitively. In each case, the different nuances and situations in which the learning did or did not take place affected the outcomes, especially where the other Involvement Attributes supported, or did not support, cognitive learning (Table 8.1).

Table 8.1 Barriers to the Participants' Learning which Reduced Involvement

	Joe	**Josie**	**Gordon**	**Jack**
Barriers to Useful Cognitive Learning	Compliance Especially with physiotherapy staff.	Misinformation and failure to discuss relevant issues with appropriate staff Misalignment of Goals	Disinterest	None Apparent
Cognitive Learning	Weak	Strong in social participation and weak in terms of physical goal management	Very Weak	Strong
Operant Learning	Stronger in Periods One and Two	Strong	Moderate	Strong
Other Involvement Attributes that Supported the Position Variably	Strong Vision Incentive, some good Goals, variably useful Disposition	Strong Vision and Incentive Misalignment of Action-based Involvement Attributes some unattainable Goals Fragile Disposition	Weak Vision and Incentive, weak goals poor Disposition	Strong Vision Incentive and Useful Goals and Disposition
Level of Involvement	Apparently Strong	Strong (social participation) Weak management of action-based goals	Weak	Strong
Locus of Control	Towards Practitioners	Towards Josie	Towards Practitioners	Towards Jack

The Participants' Learning

Joe's overall compliance was an important barrier to cognitive learning as he often failed to take some opportunities to learn and use that learning to adjust (Table 8.1). This was evident in his work with all the staff of the Intermediate Care unit. Joe said

> "I make no decisions I just leave it to them. They say you're going to get washed I lie here and they wash. If you're going in the bath, put us in the bath. If I'm going for physio. I just say right I'm ready for physio" (1, 294-298).

Strategies like this reduce cognitive learning, involvement and opportunities for functional progress, even in the presence of a strong Vision and Incentive. Joe's strategy demonstrated that although he wanted to go home, Cognitive Development was not a high priority. Joe did not want to learn about himself and his role in the management of his physiotherapy and this was a major contributor to Joe's inability to progress with his rehabilitation in Period Four, at home. This situation represented an imbalance in Joe's Involvement Attributes.

The absence of Cognitive Development, demonstrated by Joe, was incomplete as he did learn cognitively in some areas, for example, when he began to carry out self-appraisals, refusing extra analgesia and thinking about the future.

> "Doctor's just been this morning and wanting to increase my pain killers but I says just hang fire 'cos at the minute it's, you know, I mean it's not too bad." (6, 60-64)
> "I don't want to start taking more powerful than I'm already taking like. I don't know what effect it will have on me body in later life" (6, 68-71).

Joe also adjusted the timescales he set for himself through conversations with the staff which demonstrated reflection.

> **"**I was told previous to coming up here that, err, umpteen people told us, the lay preacher (hospital chaplain) that used to come downstairs, he used to always pick on me I don't know why, different ones have said "Oh! ward [Name]. As soon as you get up there it won't be long before you get out the door. But, er, the consultant's been this morning she says, you know it's going to be a long job I says I understand that."

This was confirmed in Period Four

> "Well my goal was to get out as quickly as possible, but it went on longer than I thought it would. I thought I would be in and out, you know within a couple of weeks but it went on to 16" [16 weeks in hospital in total including seven weeks in the Intermediate Care unit]. (19, 106-110)

However, the answers Joe was given, about the timescale, were practitioner-led, paternalistic (not negotiated or shared), and were accepted by Joe. This situation was consistent with operant learning and the compliance Joe demonstrated prior to his acute hospitalisation (discussed in the participants' background, chapter five-Constructions) and his rehabilitation stay.

A failure to learn cognitively had consequences for the participants in terms of their cognitive dependence which kept the locus of control with the practitioners and is an indicator of weaker involvement. Joe demonstrated this cognitive dependence in his relationship with the physiotherapist, who gave him paternalistic encouragement by telling him she understood that he was trying and that he was not a person who would evade the work he needed to do.

> "Yes and I give it a go if I can do it I'll do it if I cannot well I have to admit defeat they said thereselves, divn't worry about [don't worry about] ....we can see your not a shirker ya kna [you know] you're willing to try anything, which I am it's the only way I'm going to get out of here" (14, 72-76).

Gordon demonstrated a more complete barrier to Cognitive Development associated with his lack of motivation, enthusiasm and strong goals, discussed in the earlier construction chapters. Gordon demonstrated that he thought he did not need to learn cognitively, he stated that it was other people's responsibility to rehabilitate him. When asked who would help him Gordon said

> "Somebody in here" (30, 207-208).

Gordon was also not concerned about his progress and was disinterested which weakened his involvement (Table 8.1). Rather than be encouraged, Gordon had to be persuaded in physiotherapy. When instigating physiotherapy, the physiotherapist said

> "[I] was just really tough with him" and told him yeah, you can do it... you can come on do it. And he did do it but he was very much just ready to give up" (38, 197-199).

Jack learned about his physiotherapy exercises and did his own exercises outside of the supervised physiotherapy times.

> "You know if you are doing physiotherapy Monday to Friday it's not much good doing nothing on Saturday and Sunday. You can lose some of the effect" (43, 95-98).

Jack had also learned cognitively about the relationship between exercise and strength. Jack also recognised the need for more physiotherapy and perceived that he had a personal responsibility to do something about it. Through these actions Jack demonstrated the value of Cognitive Development to involvement and moved the locus of control nearer to him. Jack's cognitive learning was recognised by the physiotherapists.

> "Jack is very on the ball with how he wants things to go" (41, 52-53).

Josie also demonstrated she was learning cognitively about her treatments and how they affected her. This was exemplified by how she managed her medication. Josie took sleeping tablets at night.

> **"**And then tonight, what is it I get tonight? Oh, two sleeping tablets as well. But I usually keep them separate because I take them later. But I think I'm taking them a bit too late because I'm not waking up in the morning. I'm missing what's going on in the morning, here" (20, 668-675).

Josie also demonstrated informational Cognitive Development; one support worker said

> "She will take on board everything that you told her, everything, and then her frame of mind depends on what is being given to her" (23,786-789).

Josie had two main strategies for obtaining information. Firstly, she was able to ask questions and listen carefully to what was said to her and secondly, Josie watched the faces of the staff. Both of these strategies were informal and were used by Josie to make decisions. For example, one of the support workers said, about Josie's leg wound

> "There is many a morning and I'll go in there and she will say "eee, what's going to happen, why am a still here, you know, what they doing this for, why is that, and she will say you know"..., I mean she

> said to me this morning, erm, everybody was attending to her leg, and she said "what's it like", and I said "not very nice", I'm not going to lie to the woman" (23, 845-854).

Josie's second strategy for obtaining information and Cognitive Development was watching the faces of the staff.

> "I watch their faces. You can tell if somebody is doing something they don't want to do. But they just take it in their stride and I'm so happy about it" (20, 764-770).

Josie was not able to discriminate among the staff who provided different types of information. She talked to all the staff available to her (mainly health care support workers, staff nurses and medical practitioners). The information she obtained from these, often socially-based conversations, was largely informal, based on personal opinions and used by Josie to make decisions. Some staff were concerned about the veracity of this informal, oral information.

> "I think she likes honesty I think she likes truth, and I think she bases her choices and decisions on what she is given because I think if you don't you're giving her... making her make false decisions and false choices really" (23, 487-493).

This concern may have been justified as, in making a decision about the move to a Nursing Home Josie said

> "One of the ones in here, one of the head ones, said there was either a choice of going into a home or having a hoist fitted at home. They were willing to fit a hoist for us at home but it would mean that I would have to be in bed 'till a carer come and got us up on the hoist and I would be sitting with a hoist on all day waiting of somebody coming in to hoist us to the toilet and that again" (26, 401-412).

On this occasion Josie was misinformed; older people in Josie's position, requiring hoists, do not have to stay in the hoist whilst in bed.

In some ways, Josie's Cognitive Development demonstrates stronger involvement concerned with developing a vision for her future and the actions related to this for which she took responsibility. However, Josie's beliefs about improving mobility, discussed in chapter six (Vision, Incentive and Goals) and her informal, covert Cognitive Development strategies and hope demonstrated a barrier to learning about her physical abilities in relation to rehabilitation (Table 8.1). Additionally, these barriers represent a misalignment between the psychological Involvement Attributes and the action-based Involvement Attributes. Alternatively, these beliefs could have been based on a reluctance to accept her physical situation during her stay in the Intermediate Care unit and the maintenance of hope. Whichever the case, this failure to learn, or misinformed learning or the interpretation of what was said to her, had a temporary positive function for Josie and longer term poor consequences.

Recognition of Impairments in Relation to the Work to be Done to Achieve Progress

A recognition and understanding of impairments in relation to the work required to be done to make progress demonstrates Cognitive Development and strengthens involvement. The participants managed this at various levels, which strengthened or weakened their involvement in their rehabilitation and care.

Although Joe realised that he needed to improve, functionally, before he returned home, he did not seem to recognise the significance of his functional impairments in relation to what needed to be done to attain improvement, so that he could return home (Table 8.2). He seemed to leave the *process* of his improvement to his practitioners. This is another demonstration that Joe was not learning cognitively but operantly, directed by the physiotherapists.

Table 8.2 Learning by the Participants through Associations between their Impairments and their rehabilitation leading to Different Levels of Staff Compensation

	Joe	**Josie**	**Gordon**	**Jack**
Recognition of Impairments Associated with the Rehabilitation Work	Did not make a significant associations	Made some misguided associations but accepted and learned about her need for care	Made very few associations	Made sound associations
Cognitive Development	Weak	Weak	Weak	Strong
Level of Operant Learning	Strong	Strong	Weak	Strong
Compensation by the Staff	Moderate, then High in Period Three	Strong	Strong	Weak
Locus of Control	Towards Practitioners	Towards Josie as the miss-alignment of goals was not discussed with the staff	Towards the practitioners	Towards Jack

When Joe was not allowed to go home, as discussed in the compliance section of chapter ten (Relationships), Joe had not cognitively learned enough about his impairments to properly appraise himself of his abilities and was surprised at his inability to succeed when he had tried hard and complied with the regime. Joe still did not realise that he was not physically ready to be discharged.

> “Body-wise I think I could manage but home improvements [Are holding things up] at the minute, I think” (16, 567-569).

This failure to recognise and understand his abilities, whilst maintaining the same goal to go home as quickly as possible, put pressure on the practitioners to discharge him home safely, rather than independently. This will be discussed in chapter ten (Relationships).

Another consequence of the participants’ failure to learn in a cognitive manner was that the staff were required to compensate for the participants’ lack of understanding and ability. For example, Gordon’s *laissez faire* attitude towards learning, occurring in the care delivered by nurses and support workers, outside of formal physiotherapy, led to care staff compensating for his limitations (Table 8.2). A staff nurse seemed to think that in another setting Gordon would have done more for himself. She didn’t seem to conceptualise her role as a rehabilitation facilitator for Gordon. The staff nurse said

> “I think possibly he could have, [done more for himself] but I think because it’s a hospital and it is a nursing setting maybe if he’d been in a more social setting he might have done more [for himself]” (34, 183-185).

When asked whether Gordon could have done more for himself Gordon’s attitude was put down to him being in an individual room and therefore isolated.

> "He might have been a bit more progressive in what he did. He might have got up a bit more; he might have walked over and had a chat with somebody. Whereas it's very secluded in the little room so I think he might have done a bit more if, maybe, the surroundings had been a little bit different for him" (34, 183-193).

The consequences of a failure to learn cognitively, led to a further weakening of Gordon's involvement by pushing the locus of control towards the practitioners.

Where there is Recognition of Limitations in relation to work to be done, Cognitive Development is demonstrated and involvement is increased. Jack recognised that he needed more stamina. Jack said

> "If I could just get more energy" (42,615).

This realistic self-appraisal was followed by other demonstrations of Jack cognitively learning about himself.

> "Oh before I get up in the morning I am feeling to see how well I can move" (43, 386-387).

Towards the end of rehabilitation and at home, Jack continued to demonstrate that he understood his limitations and continued to make self-appraisals.

> "It's having to build my personal strength. It's the strength that's lacking you know" (48, 156-158).
>
> "The main problem I have at the minute is strength and of course I have still got a disability in the left hand side in this hand and leg. I have still (Table 8.2) got to build up a better grip on this" (48, 483-490).
> "So if I have to get up from a seat I have to push myself up cos you don't think about it normally you just get up out of your seat, I have got to think where can I put my hands to push myself up. The physiotherapy obviously helps that but it's not initially the thing that matters it's getting my strength up" (47,162-167).

Jack demonstrated a positive association between involvement and Cognitive Development through the understanding of the association between his impairments and the process of improvement, and then by carrying out self-appraisals and making a personal effort to increase his stamina. This self-appraisal, problem-solving and adjusting, set Jack apart from Joe and Gordon. Joe had goals but not the wherewithal to take a personal role in the process of their achievement, Gordon had vague goals and, like Joe, did not think it was his role to learn how to achieve them.

Josie's recognition of her limitations was complex and not associated with a reduction of impairment because, realistically, there was unlikely to be significant functional improvement. Josie's vision of her future life in a Nursing Home was misaligned with action-based mobility goals. This misalignment of her goals to her abilities reduced opportunities for Cognitive Development and Involvement in this respect.

Seeks Personal Solutions to Progression Barriers

Sometimes the organisation was unable to meet all the needs of the participants. The participants' reaction to this, when it occurred, demonstrated different levels of involvement (Table 8.3). One of these that affected the participants equally was the availability of the physiotherapists and physiotherapy.

Table 8.3 Demonstrations of Cognitive Development and Different Abilities to Seek Solutions to Barriers to Progression

	Joe	**Josie**	**Gordon**	**Jack**
Seeks Personal Solutions to Perceived Barriers to Progression	Tried but the solutions remained the responsibility of the staff, especially in rehabilitation	Was very successful over obtaining what she wanted and managing others in her care	Did not try	Was very successful at obtaining what he wanted in rehabilitation and care
Cognitive Development	Weak	Very Strong	Very Weak	Strong
Involvement	Apparently Strong but actually, Weaker	Strong with respect to her move to the Nursing Home weak with respect to the misalignment of her physical goals with her Vision	Weak	Strong
Locus of Control	Towards the Practitioners	Towards Josie	Towards the Practitioners	Towards Jack

For reasons such as holidays, sickness and different physiotherapy rotas, physiotherapy time for individuals was often reduced, particularly at weekends and bank holidays. Initially older people, new to the Intermediate Care unit, had formal physiotherapy, one-to-one, in the morning. As the older people progressed, their physiotherapy sessions were allocated in the afternoon of each working day. The cognitive learning about their physiotherapy was demonstrated by the participants' reaction to this. Some saw it as a progression barrier, wanted extra physiotherapy and acted accordingly. Others did not see the lack of physiotherapy as a barrier and waited for the next physiotherapy session. The former participants had stronger involvement than the latter.

The need for continuous physiotherapy was recognised by Joe and Jack as a progression barrier and demonstrates some Cognitive Development. The issue for Joe was timing. Joe suggested going to physiotherapy in the morning as he might have more energy.

> “If you give us a go in the morning I don’t know if I will have more energy in the morning whether I don’t I’m just grasping really like just to try something” (16, 34-39).

When this was not possible, the physiotherapist suggested to Joe that he should exercise outside of formal physiotherapy, but it was unclear whether he did this frequently or regularly. The locus of control for the extra exercises was towards the practitioner, reflecting that although Joe recognised the need for more physiotherapy, he was guided to a solution by physiotherapists (Table 8.3). Additionally, Joe’s uptake of the solution was unconvincing and he was not concerned about weekends or bank holidays when there was no physiotherapy planned. These issues suggest that Joe’s Cognitive Development from this situation was weak.

> **“Did he, has he ever said to you am I doing enough exercises? Can I do more exercises?”**
> “Never no. I do keep saying to him erm, right, Have you done your exercises in your room? And, surprise, surprise he always says “Oh yes I have, yes I have” but I've never actually gone in and witnessed him doing anything. Whenever you go to him he is usually laid on his bed and, erm, and I don't really think he does do that much exercise in his own time” (17, 71-86).

Jack behaved in a different way. The significant issue for Jack was the cancellation of physiotherapy sessions. Jack could not have a particular session because

> "They didn't have the time because we had people on holiday" (44, 309-311).

Jack circumvented a perceived lack of physiotherapy by doing physiotherapy on his own, during the day and, significantly, at weekends, demonstrating stronger Cognitive Development and involvement (Table 8.3).

> "Yes I could [do more formal physiotherapy] but I do a lot on my own anyway sitting in the chair, ankle exercises and leg exercises and arm. So overall I think it's pretty sound" (46 531).

> "You know if you are doing physiotherapy Monday to Friday it's not much good doing nothing on Saturday and Sunday. You can lose some of the effect" (43, 95-98).

This attitude contrasts with that of Joe, and indicates stronger involvement. Joe was always willing to do what he was told to do but was not as innovative as Jack in his approach. Joe did not think of the weekends as an opportunity and was not active in learning about himself and his way forward in the Intermediate Care unit. Jack took the opportunity to push himself along his own pathway, demonstrating a will to take personal control of the situation and move the locus of control towards him. When Joe did extra exercises it was because he was told to do them and he did the exercises when he was bored, until he was bored with the exercises.

> **"Did you do exercises on your own?"**
> "Oh yes on the bed I used to do the leg exercises as I say I soon got tired of doing them" (19,158-162).

Another way of demonstrating a lack of Cognitive Development was not to look for, or see, progression barriers. Although Gordon stated that he wanted more physiotherapy, he thought it was up to the physiotherapists to do it, which demonstrated little Cognitive Development, if any, and weakened his involvement (Table 8.3). So, unlike Joe and Jack, Gordon did not seem concerned about the level of physiotherapy.

When discussing whether the physiotherapist thought Gordon would ask for what he wanted the physiotherapist said

> "I don't think he would do that, that's just the type of person he is" (31, 220-221).

Gordon's failure to recognise barriers to progression was seen most clearly when he was discharged from the Intermediate Care unit. When Gordon went home he was given a "care package."

When discussing the care package in terms of respite for Gordon's daughter, Gordon stated

> "It will help her in the morning because she works in the morning" (32, 267).

This demonstrates that Gordon had the expectation that his daughter would always compensate for the things Gordon did not do. There was no mention of what Gordon would do for himself (Table 8.3).

Like Jack, Josie sought personal solutions to progression barriers, demonstrating Cognitive Development and strengthening her involvement. This learning was not about improving her physical abilities in the way that

Jack organised himself, but to be more comfortable in the Intermediate Care unit. Even so, the thought processes demonstrated an element of planning and the use of external resources similar to Jack, who took up extra exercises to maintain his physiotherapy and Joe who tried to get his physiotherapy session changed to a time in the day when he had more energy. Examples of this planning demonstrate the interest that Josie took in herself and her involvement whilst in the Intermediate Care unit. These examples included, altering her diet.

> "I've stopped having my orange juice in case I mess the bed too much" (20, 1055-1056).

Relatives also brought in

> "Fruit, paper hankies drinks, erm crisps sandwiches, bottles of beer" (26, 889-891).

.

When Josie could not get the help she planned, she often found ways to circumvent the problems, for example, when Josie's cousin could not attend at visiting time and bring in a supper, Josie ordered crackers and cheese as part of her tea and saved them for a supper (10, 1021-1024)

This organisational ability was not restricted to Josie's diet. Josie asked relatives to bring in dry shampoo for her hair

> "Because I can't get my hair washed here" (20, 992).

Additionally, Josie's relatives brought in some more absorbent pads, so that Josie did not have to have her bed changed twice a day. She called them

> "Posh Inco pads" (25, 462-463).

Josie was also interested in her leg wound, how this was dressed each day and the healing progress being made. Although Josie was reliant on the nurses to dress the wound, she tried to make sure of the availability of resources. When the cream used on Josie's leg wound was found to be effective, Josie was interested to know whether the ward had enough for future dressings.

> **[Nurse]** "**This stuff's really good. So impressed with it."**
> [Josie] "So have we got enough left for the rest of the week?"
> **"No we've ordered some it should be here tomorrow."**
> "And what about these gauze things and that you like better than the cling film?"
> **"That's been ordered as well at the same time."**
> "Oh right good" (21, 562-578).

In these ways Josie was also able to control her personal environment in the Intermediate Care unit very well, and her involvement in this area was stronger than Jack, Joe and Gordon as she was interested in managing those things she could not do for herself. These actions moved the locus of control towards Josie (Table 8.3).

Josie's ability to organise others, something that the other participants did not try to do, was also evident, further demonstrating Cognitive Development. When the nurses finished dressing Josie's leg wound Josie took charge of her environment asking

> "Is my thing [catheter] still filling up alright?"
> "Right, now I want my thing [table]".
> **[Nurse] "I've got it here."**
> "No! I have it up here for my dinner, man darling" (21, 1394-1396).

Sometimes Josie tried to organise who carried out her personal hygiene and change her bed.

> "She will say who is on this morning? Can so and so look after me?" (25, 849-851).

Another aspect of this Cognitive Development was Josie's ability to plan for future, potential problems. For example, Josie planned ahead in her care

> "I say to them if its [the pillow] not right in 10-15 minutes can I buzz you again and will you come and put it right cos it's funny the difference a pillow makes when your feet's on it" (26, 1036-1041).
>
> "I keep telling them to check my [urine] bag cos I prefer a night bag on because I'm frightened the other one gets too full sometimes, but some of them remember automatically" (26,1047-1052).

In summary, Joe was interested in problem-solving but relied on the staff to do most of this for him, especially in rehabilitation, so his Cognitive Development was weak. Jack learned to take some responsibility for himself using the resources on hand while obtaining other resources he needed, indicating stronger Cognitive Development. Josie did the same and, in addition, was able to organise the staff and her relatives to help her achieve her care goals, also demonstrating stronger Cognitive Development in this respect. Gordon was not interested in problem-solving, passing the burden of his rehabilitation and his functional and social life on to others. Gordon therefore, demonstrated little Cognitive Development and weakened his Involvement (Table 8.3).

Learning after Going Home

As the participants moved from the Intermediate Care unit, it might be expected that their Cognitive Development would increase with a reduction in the paternalistic direction of the staff of the Intermediate Care unit. Each participant had a new opportunity to learn about their limitations, without the interventions of the Intermediate Care staff. However, this transition was different for each participant who demonstrated different levels of Cognitive Development and involvement. This is summarised in Table 8.4.

Table 8.4 A summary of the Participants' Involvement after Returning Home

	Joe	**Josie**	**Gordon**	**Jack**
Learning through Self-Appraisal	Yes becoming more realistic	Yes becoming more realistic	No	Yes-realistic
Attitude	Perplexed	Coping	Deferent to others	Confident, possibly over confident
Hopeful	Yes	Despair	No	Yes
Enthusiasm for Functional Improvement	Yes	Faltering	No	Yes
Able to Improve Functionally	No	No	Yes, if Motivated Externally	Yes
Improving Functionally	Static	Static	No, may deteriorate	Yes
Home Circumstances helping?	No	No	No	Yes
Level of Cognitive Development	Strengthening slowly from that in Rehabilitation	Strong socially Becoming evident physically	Very weak	Strong
Locus of control	Towards the practitioners who ordered the home alterations	Toward Josie except that she began to despair	Towards Gordon's daughter and carers	Towards Jack

Jack became more cognitively independent, making self-appraisals and understanding more about solutions that compensated for his functional impairments. Jack's Cognitive Development was experiential. In the first week at home Jack fell twice but seemed unconcerned, reflecting his continued learning about his abilities and limitations. Jack's words of optimism contained the same belief and hope that he had demonstrated in Period One in the Intermediate Care unit. By broadening his physical boundaries he continued to learn cognitively with strong involvement (Table 8.4).

> "I have over-balanced. I knew I was going to fall I could feel myself going so you, more or less, role yourself down. Rather than clashing, you kind of roll" (49,119-125).
>
> "One of the hazards about this business, I find, is you knock things over and you drop things on the floor and quite easily. Without thinking I'll bend down and pick up. Without thinking I'll just go and pick that up and you keel over. You have got to think can I reach that, you know. I'll manage it but you have to look for something to lean on or support you so it takes a long time to adjust" (49, 413-423).

This learning led to insights into how to manage the risk of falling at home (chapter nine (Risk Management) and, through this, Jack demonstrated his growing self-awareness, confidence and the ability to make decisions and choices.

Conversely, Joe did not demonstrate a significant strengthening of Cognitive Development and was "terrified of falling" because the planned alterations to his home had not been made. Joe was waiting for someone to come and help him. He was still expecting the locus of control to be with others (Table 8.4). Joe thought that it may have been better if the alterations had been carried out before his discharge.

> "Well looking at erm my partner's point of view it would have been better if all these jobs had been done before I come home. Do you get what I mean?"
> **"Yes".**
> "You know the likes of the step and my chair and the shower is going to be a long job like I think erm. But likes of the chair and the step well I've got gout" (19, 229-231).

Joe's learning differed from that of Jack as it was not independent. Joe was wondering about how to expedite the home alterations he had been promised and how others would prevent him falling, rather than what he could do for himself.

Josie was learning about her care in the Nursing Home environment. She was beginning to accept the extent of her impairments (Table 8.4). Josie's leg had healed in the Intermediate Care unit prior to discharge, but this had become swollen again and red enough for a dressing to be required. Josie was concerned that this would keep her bedfast.

> "I keep thinking well my leg's getting flamin' worse what with that and with getting us on the right dose of warfarin. I keep thinking, am I ever, ever going to get out of bed. I just don't know" (29, 232-236).

Josie was physically dependent on the staff because she was bedfast and was emotionally dependent on the staff and her family to help her to maintain self-respect. These dependencies did not change throughout the rehabilitation stay or after discharge. However, in the Nursing Home, Josie began to learn, cognitively, about how she could make herself more comfortable. Josie started to develop relationships with the staff of the Nursing Home as she had done in the Intermediate Care unit. This was demonstrated when Josie discussed her daily bed bath.

> "Well when I first came here I didn't know when I was getting my bed bath right? There so busy and they've got so many people to see to. And then they would sometimes say "well you had visitors all afternoon". So I said "Well I cannot go on like this I like to be sorted out." So they said, "Well if you are willing, the night shift would give you a bed bath. But they go off at 8am so you must be willing to have it at 7am." So I says "Right fair enough." So I got our [Name] to bring a little alarm clock in and I set it for

> 7am. And if they weren't here I used to press my buzzer but now they're automatically here. They come about 20 to 7 and I have my bed bath and get my night dress changed and then I'm clean for the day" (29, 152-164).

For Gordon, the functional success of rehabilitation was limited. At the end of his rehabilitation stay Gordon was not independent, but was able to stand from sitting and walk around his home, potentially reducing the burden on others, particularly Gordon's daughter and the community care team. Gordon knew he was going to need help, on which he relied.

> "The occupational therapist expected that it will reduce the onus on her (Gordon's daughter) to do everything for him" (34,124).

There was no significant increase in Gordon's Cognitive Development. At home, the centre of the resources needed by Gordon moved slightly from his daughter towards his carers delivering a care package. However, this was still an external locus of control and together, these issues demonstrated Gordon's weak involvement (Table 8.4).

The care package was set up by the physiotherapists, who wanted

> "Somebody regularly coming in to get him washed and ready in the morning, you know set him on his way, make sure he's got everything to get cracking and get his breakfast. So she's (Gordon's daughter) got time to do the nice things, to be the daughter" (34, 125-129).

This care package compensated for the improvements Gordon could have made if he had a greater involvement in, for example pre-functional and functional goals.

The instigation of the care package worked to reduce Gordon's Cognitive Development and involvement further. Although Gordon stated that he was not concerned about falling when he rose from his chair at home, and that he was capable of putting himself to bed, he was not allowed to do this.

> **"Would you like to do it [go to bed] on your own?"**
> "I suppose so" (39, 239-241).
> **"Can you put yourself to bed Gordon?"**
> "Yeah." (39,225-227)
> **"And do you think you'd fall if you did it (go to bed) on your own?**
> "No not now" (39, 234-237).

Gordon reiterated this later in the same interview when he said

> "I don't fall now." (39, 433)

However, Gordon agreed that the carers would put him to bed.

> "To see that I don't fall" (39, 232).

The reason for this was that Gordon's daughter wanted to make sure he was safe

> "Well I would feel safer if they still put you to bed cos then I know he's in bed properly" 39, 245-247).
>
> "Cos I won't see him 'til 9:30am the next morning" (39, 251-252).
> "…and that's what worries me in case he falls" (39,283-284).
> "He could put himself to bed, but I would be frightened in case he fell when there's nobody here" (39, 639-642).

Gordon seemed to be less worried about falling than his daughter

> " **[Daughter**] He doesn't bother. It worries me but it doesn't bother him" (39, 290-291).

Gordon's decision to let the carers put him to bed meant that he had to go to bed earlier than he would normally do so. Gordon's daughter could not put Gordon to bed at his preferred time because she went to bed at 9pm in preparation for her work which commenced at 4:30am each morning (39, 621-624). Gordon did protest at this, but accepted a rebuttal

> "I tell them I'm not ready for bed and that's it (39, 494-498)

> "There's nothing I can do" (39, 608).

Gordon's bed time was moved from 10:30pm to 8pm (39, 600-616).

Gordon's daughter was pleased with this

> "But I feel safe although he has to go to bed at 8 o'clock I am sort of not worrying because I know that he will be in bed and he is safe until the next morning when the carer comes in" (39, 659-663).

Gordon's home circumstances meant that he was still not taking personal responsibility for his development, and so he was learning less and was less involved in his rehabilitation than Jack and Josie. Gordon's locus of control was still toward those caring for him. Gordon's external resources, the carers and his daughter, conspired against Gordon in a paternalistic way, to decrease his independence, opportunities to learn and weaken his involvement.

These circumstances are similar to Josie who, in the Nursing Home, was more restricted than she had planned due to her physical impairments and the paternalistic approach of the carers. However, Josie's circumstances differ because she did not have the functional improvement opportunities of Gordon. Gordon's position differs slightly from Joe whose home circumstances, the structural improvements in the hands of others, conspired to hold Joe back from being able to do what he wanted. Gordon's position contrasts strongly with Jack, whose home circumstances assisted his further improvement. This will be discussed in chapter ten (Relationships).

Conclusion

Cognitive development is an integral part of involvement associated with the ability and willingness to learn and focus on rehabilitation in terms of the work to be done to achieve progress and seeking solutions to progression barriers. The participants demonstrated cognitive development at different levels. Where trust in the practitioners was very high cognitive development seemed weak. However cognitive development also did not occur in one participant who was disinterested. Where cognitive development did occur significantly, progress in rehabilitation was strong.

Chapter Nine: Risk Management

Introduction

Risk management is concerned with the way the participants explore their abilities and surroundings. This exploration is a product of the psychologically-based Involvement Attributes and operates in the action-based Involvement Attributes. This chapter discusses involvement through the risk management strategies that each of the participants employed during their rehabilitation stay and at home. These Risk Management strategies were demonstrated by the way the participants behaved in relation to the decisions they made, or did not make, and their perceived risks. Risk Management is discussed in terms of the axial codes within it, which are: Recognises Personal Limitations and Associated Risk Factors, Decision-making, Personal Responsibility and Control, Takes Steps to Reduce Risk and Manages Uncertainty.

Recognises Personal Limitations and Associated Risk Factors

This part of involvement associates the limitations of the participant to their own personal risk factors in the Intermediate Care unit. Involvement was weakest when there was a failure to recognise personal limitations and the associated risk factors, and when the locus of control moved away from the participant. Involvement was strongest when the converse occurred (Table 9.1).

Table 9.1 The Development of Different Risk Management Strategies during the rehabilitation stay and their effect on Involvement

	Joe	**Josie**	**Gordon**	**Jack**
Recognises the Relationship between Impairments and Risk Factors	No	Yes for move into the Nursing Home No for functional improvement	Yes	Yes
Concerned about the level of impairment	Yes	Yes	No	Yes
Realised Personal Exploration was Required	Not really	Yes, but not in functional improvement	No	Yes
Allowed others to risk manage	Yes	Yes, in care	Yes	Yes, then reduced over time
Prepared for Personal Exploration	A little	Yes but not functional exploration	No	Yes
Took Personal Responsibility for Exploration	A little	Yes but not functional exploration	No	Yes
Locus of Control	Towards others	Towards Josie where possible	Towards others	Towards Jack
Level of Involvement	Moderate	Strong	Weak	Strong

The participants recognised their personal limitations to different extents, at different times and for different reasons. In Joe's case, in the Intermediate Care unit, he did not recognise his limitations because he felt he did not know enough to help himself and he did not understand what the physiotherapist was trying to do. This is strongly associated with his lack of Cognitive Development during rehabilitation and weakened Joe's Involvement. Joe did what he was told and left risk management to others.

> “Me taking the lead, I dare say if I really pushed myself I could do more but I don’t want to sicken myself” (14, 33-34).

> “[I am] ...not gened up enough on, er, physiotherapy to know what is good and which is not good you know” (16, 437-439).

This was less important at the beginning of the rehabilitation and was covered up during this period of functional weakness. It became more obvious when the locus of control could have moved towards Joe, later in rehabilitation (Table 9.1).

Gordon’s *laissez faire* attitude to his rehabilitation, discussed in chapter seven (Disposition), meant that he also relied on the practitioners for risk management but, unlike Joe, Gordon was unconcerned with the level of his limitations and associated risk factors which weakened his level of involvement even further. Gordon did not attempt to move the locus of control towards himself (Table 9.1).

> “When the girls come and get us I try to get up” (30, 257).
> “Anything for a quiet life” (30, 170).

The reason for poor recognition of limitations may not have been in the hands of the participants alone. In Josie’s case, there was strong evidence that she was encouraged to let the staff do more for her than was necessary, allowing the locus of control to be kept towards the staff, as discussed in chapter ten (Relationships). The acceptance of Josie’s physical limitations by the staff was extreme at times and, at these times, little effort was given over to ask Josie to help herself. For example, when asked how Josie felt when staff cared for her she said

> "I just let them because I think, well, they say you go back to being like a baby – I might as well just go back to being a baby" (20, 806-809).

The response to this paternalistic pressure is a factor within involvement (Table 9.1) and is discussed in chapter eleven (Study Discussion).

Josie seemed to not enjoy this position but, when being cared for, was unable to move the locus of control towards herself which weakened her involvement in this aspect of her care (Table 9.1).

When her leg was being dressed, Josie demonstrated her desire for independence in a sarcastic way.

> "[Name] does all the work, I just lay here."
> "It's as though I'm one of those, you know, getting sprayed with fig leaves and grapes fed to them" (21,609-610).

Josie was uncomfortable having someone do everything for her and tried to help.

> "[Josie]: Can I help you in any way?"
> **"[Nurse]: No you're alright there, lovely, you're OK" (11, 239-242).**
> "Right do you want me to turn over now?" (24, 264-266).

Jack approached this situation differently. Although he was unable to do much for himself at the beginning of his rehabilitation stay, his understanding of the possible temporary nature of this meant that, cognitively, he kept the locus of control towards himself and demonstrated increased involvement (Table 9.1). Jack understood himself and his position well enough to say

> "I don't think I'm taking any [risks] at all. The only thing I do apart from the physiotherapy and walking back from the gym is going in the shower and that's not really a risk is it?" (44, 162-165).

Jack's work in the Intermediate Care unit may not have been thought of as a risk by Jack, because he was always accompanied when carrying out tasks.

> "Oh they don't let me do anything alone. There's always somebody with me" (43, 474-478).

> "I think it's sensible because I'm not 100% steady yet in mobility, you know, walking and going around. I still feel I could topple over" (43, 483-485).

However, in line with his understanding, Jack was cautious, which was something that was not exhibited by Gordon or Joe, and is another sign of stronger involvement. When walking back from the gym with his Zimmer frame Jack felt

> "Safe but reassured that the chair is handy if I need it" (43, 179-180).

There are other ways of recognising limitations and associated risk factors apart from those concerned with physical injury. This was exemplified when Josie made the decision to go into a Nursing Home (Table 9.1). This was reasoned logically and is dealt with under Decision-making in this chapter.

The participants' position about the recognition of limitations and associated risk factors was not static during rehabilitation. The positions of Joe and Jack changed as they improved functionally, taking more risks by testing out their regained abilities, as discussed in chapter seven (Disposition). Although Gordon improved functionally, he did not seem to want to become independent or take risks. Josie's physical helplessness did not diminish, making functional risks difficult for her.

Risk Management Post-Discharge

On discharge, the Risk Management was passed over to the participants. This meant that the locus of control moved from an Intermediate Care base, to a family base. Joe, and his partner, were left on their own with a promise of some home alterations that would reduce risk and facilitate movement around and outside his home. Gordon's risks were transferred to himself, his daughter and the staff of a care company employed to attend him. Risks for Josie were transferred to Josie and the Nursing Home staff and the risks for Jack were transferred to Jack, his wife and a community physiotherapist who attended Jack for one hour weekly.

All the participants behaved differently after discharge. Their differences are summarised in Table 9.2.

Table 9.2 Reactions to Risk Management *Post*-Discharge

Reaction	**Joe**	**Josie**	**Gordon**	**Jack**
Knowing how to progress personally	Only through others	No, did not want to be reliant on others	Yes, but accepting of personal reliance	Yes
Attitude	Perplexed	Despairing	Unconcerned	Eager
Prepared for discharge consequences	No	No	Yes but reliant	Yes and self- reliant Possibly too self-reliant
Acceptance of limitations	No, formed new goals but not Pre-Functional	Increasing	Yes	No
Acceptance of Compensation	Yes, but waiting for others to act	Yes, reluctantly	Yes	No
Taking physical risks	Yes, a little	No	No deferent to others	Yes, Eager Possibly too eager
Level of Involvement	A little stronger	Stronger in that she was more realistic and weaker because of her despair	Weak	Weak

Joe had demonstrated weaker involvement in the Intermediate Care unit, through a failure of Cognitive Development. When the direction of the physiotherapists was removed after discharge, Joe did not know what to do and became perplexed because the staff were no longer around to tell him what to do (this is discussed in chapter ten (Relationships). Joe rationalised that he was discharged from the Intermediate Care unit because there was no more that other people could do for him.

> **"What do you think was the thing that helped them decide to say you can go home now?" (19, 201-203).**
>
> "In my opinion they couldn't do any more for us. It was up to myself. I mean I'd done my physio. to the best of my ability and the doctors are erm can do no more really like" (19, 204-208).

Before discharge Joe did not discuss what he might do for himself. After discharge, Joe's future was in his own hands but he was unready to manage this change and move the locus of control towards himself. At home the associations between Joe's impairments and risk factors began to change, as Joe began to learn about this relationship. In the week *post*-discharge Joe had fallen from his bed, found it difficult getting up from the floor and stumbled whilst walking.

> "Well I've stumbled a couple of times, like. But I've only ever went down once, as I say, when I rolled out of bed" (19, 452-454).

Joe began to recognise his limitations and felt anxious, demonstrating a stronger involvement as he began to experience the effects of the change in the locus of control.

> "I'm terrified in case I fall" (19, 24-25).
> "I'm terrified to try to walk in case I stumble, like, you know" (19, 62).

Joe was beginning to strengthen his involvement in his functional development through an increase in Cognitive Development: something he had been unable to do in the Intermediate Care unit. However, his solutions were not concerned with how he could help himself, for example, Joe still did not have pre-functional goals. Jim thought he could improve by the installation of his promised home alterations, which would reduce the help he needed from his partner, as discussed in chapter eight (Cognitive Development). Joe's risk position, *post*-discharge is summarised in (Table 9.2).

Jack was able to move forward based on a strong Vision Incentive and Goals and Cognitive Development. Jack was more able to explore his abilities and environment than Joe and was much more prepared for the consequences of his discharge than Joe.

In the first week at home, Jack fell twice, similar to Joe, but this was not too much of a concern to Jack. Where Joe's falls had made him terrified, Jack's falls were treated as part of the learning process, as discussed in chapter eight (Cognitive Development).

Jack, unlike Joe, had more understanding of the risks he was taking relative to his impairments and limitations. Instead of being terrified, Jack tried to be careful.

> "There are risks of becoming too confident and overstretching further than you can really. You know that you cannot make it but you still try... so I'm being very careful. As I say I have fallen twice. I don't intend to fall over any more" (48, 633-638).

Also, Jack understood his limitations, which strengthened his involvement further

> "The thing I am disappointed in is my own weakness. That has got nothing to do with the hospital, it is the disability from the brain operations they have left me very weak ...The main problem I have at the minute is strength and of course I have still got a disability in the left hand side in this hand and leg. I have still got to build up a better grip on this" (49, 483-490).

Jack also still had pre-functional goals.

> "So if I have to get up from a seat I have to push myself up cos you don't think about it normally you just get up out of your seat, I have got to think where can I put my hands to push myself up. The physiotherapy obviously helps that but it's not initially the thing that matters it's getting my strength up" (49,162-167).

The physiotherapist wanted Jack to accept his limitations to reduce the likelihood of falling.

> "Well I'd like to think he'd accept his limitations and I am not sure really how much he is actually going to get out [of his home when discharged]. That's a little bit unknown to me. I don't know how much better he's going to get with his mobility and his stamina and everything. I mean he might get a little bit better. I am not sure I could not imagine him going out by himself" (47, 323-329).

Jack also demonstrated a strong involvement by taking the occupational therapist's comments as advice and not instruction. Largely, Jack seemed unconcerned about her predictions. In this way, Jack demonstrated that the locus of control had moved significantly towards him.

> "[Jack] is still quite a high falls risk indoors 7/10 and outdoors 10/10" (47, 198).

Jack's risk position *post*-discharge is summarised in Table 9.2. It may be that Jack's risk position was stronger than his physical ability. This is discussed in chapter eleven (Study Discussion).

Of the four participants, Gordon accepted the most compensation from others for his abilities. Gordon took the least risk and had the weakest level of involvement *post*-discharge in this respect. After discharge from the Intermediate Care unit, Gordon was functionally able enough to answer the door for the last research interview in Period Four. However, Gordon did not consider further personal improvement through his own efforts, unlike Jack, or through the efforts of others, unlike Joe. Gordon had no further goals. The physiotherapist's suggestion that Gordon might deteriorate once at home was likely to be correct.

> "It's basically because I'm just worried that when Gordon goes home he's going to get into that chair and he's just going to sit there. And

> when he does come to transfer, he will be stiff and it might be that he'll have a couple of transfers that aren't as safe and I'm just worried that he'll then start to deteriorate" (35, 161-165).

Additionally, after discharge, Gordon's daughter demonstrated a risk-averse attitude towards Gordon falling whilst going to bed. Gordon's daughter wanted the carers to put Gordon to bed even though he felt he would not fall as discussed earlier in this chapter. Gordon's risk position *post*-discharge position is summarised in Table 9.2.

In the Intermediate Care unit, the risks that Josie took were in making decisions about where her care would take place (discussed under decision-making in this chapter). In the Nursing Home, Josie began to allow herself to recognise the association between her impairments and risk factors. Josie began to accept that she would not improve physically and that her hopes of mobility, using a scooter, were unlikely to come to fruition. This went some way to repair the misalignment between the psychological Involvement Attributes and the action-based Involvement Attributes but caused her emotional distress which weakened her involvement once more. Josie's risk position *post*-discharge is summarised in Table 9.2.

Decision-making, Personal Responsibility and Control

As the participants moved through their rehabilitation stay, the way they approached their rehabilitation with regard to decision-making, personal responsibility and control began to differ (Table 9.3).

Table 9.3 A Summary of how the Participants Differed in their Decision-making, Personal Responsibility and Control during and after the Rehabilitation period

Decision-Making Stance	**Joe**	**Josie**	**Gordon**	**Jack**
Makes Decisions about Rehabilitation where Possible	No	Yes	No	Yes
Shows Personal Responsibility and Control where Possible	No	Yes	No	Yes
Accepts Paternalism	Yes	Yes (with reservations)	Yes	Yes (with tolerance)
Has the Will to Progress	Yes	Yes	No	Yes
Locus of Control Movements during Rehabilitation and After Discharge	Remains with the staff and only begins to move towards Joe after discharge	Remains with the staff for functional issues but not cognitive issues	Remains with the staff in the Intermediate Care unit and is transferred to Gordon's daughter and carers on discharge	Moves towards Jack

Jack moved from tolerating a paternalistic approach, through an interpretive approach, towards shared decision-making, increasing his personal responsibility for rehabilitation. This process led to the locus of control moving away from the staff and towards Jack and demonstrated increased involvement. Joe and Gordon accepted the paternalistic decision-making approach of the staff took little personal responsibility throughout their stay in the Intermediate Care unit and allowed the locus of control to remain with the staff. However, this was more extreme with Gordon as he needed much more encouragement than Joe. Josie controlled her environment whilst in the Intermediate Care unit as best she could. Josie made decisions about her future and about how she would be cared for and so demonstrated increased responsibility and involvement. However, she also often accepted a paternalistic decision-making process over her personal care from some members of the staff, irrespective of their grade and ability.

These narratives can be divided into three positions summarised in Table 9.4.

Table 9.4 A Summary of Three Different Positions with regard to Decision-Making

Position Number	**Decision-Making Position statement**	**Participants' main stance**	**Level of Involvement**
1	Was interested but left this to others	Joe and to some extent Josie	Weak
2	Was not interested and abdicated from decision-making	Gordon	Very Weak
3	Was interested, took advice and made personal decisions	Jack and to some extent, Josie	Strong

The first position (Table 9.4), which demonstrates a weaker involvement, is to be interested but leave decisions to others when there is opportunity. Joe did not take many decisions or take personal responsibility or control of his care whilst in the Intermediate Care unit, even though he stated that he wanted to be involved.

> "Well at the minute it's [involvement is] not important er, but when I get on the move ya kna it will be very important to be able to do more for myself than I have been doing just lying here" (11, 347-351).

Joe's strategy was to make few decisions, do what he was told and to work hard in his physiotherapy. Joe behaved as if he was not part of the decision-making process and trusted in the paternalism of the practitioners accepting that they knew what he needed to know. Rather than make decisions for himself, Joe thought his role was to help the staff.

> “I make no decisions I just leave it to them” (11, 107).

The trust that Joe put in the staff seemed to create, within him, a risk-averse dependency. Even when Joe did extra exercises, it was under the direction of the physiotherapists, and Joe did not associate the extra exercises directly with the achievement of pre-functional or functional goals like Jack did, but carried out instructions using exercise to reduce boredom.

> “Well I do them [extra exercises] every hour. Every hour I do them maybe 10 leg movements 5 times. I get up and down 10 times every 20 minutes. I couldn’t do it continuously it’s very tiring but it’s ok if you don’t sicken yourself. When you feel a bit bored do it” (14, 10-13).

Although this was Joe’s main decision-making stance, he did learn from his experiences with other medications, like Indocid for his arthritis which led to his temporary kidney failure (see background of participants). Joe decided against stronger analgesia fearing it might precipitate another acute illness later in life.

> “Doctor’s just been this morning and wanting to increase me pain killers but I says just hang fire cos at the minute it’s, you know, I mean it’s not too bad” (16, 60-64).

> “I don’t want to start taking more powerful than I’m already taking like. I don’t know what effect it will have on my body in later life” (6, 68-71).

The second position (Table 9.4) that also demonstrates weaker involvement, was taken by Gordon. Superficially this was the same as Joe’s position, as

Gordon accepted the paternalistic position of the staff. However, Gordon made few decisions and was happier than Joe for the decisions to be made for him.

> "[I.] will do my best under their instruction" (30, 213-214).

Gordon did not think there were any decisions to make about extra exercises and was happy to let others do things for him. If the nurses did ask if he wanted a shower, Gordon would respond making a decision but if the nurses did not ask Gordon stated

> "I would have just left it to them" (30, 166 311).

Additionally, Gordon did not take personal control of his situation and he continued to require more persuasion and help than Joe. This was demonstrated in Period Two in a conversation about responsibility.

> **"What's going to stop you going downhill again?"**
> "I don't know. No idea"
> **"Whose responsibility is it to help you to stop going downhill again do you think?"**
> "Nobody's, just myself."
> **Just yourself? So what responsibility are you going to take?"**
> "None" (35, 419-426).

When asked what else he, Gordon, would like to be able to do, he said

> "Oh [I am] just happy the way I am" (35,336).

In a similar way to Joe, Gordon did not take any responsibility for the discharge. Gordon said he was discharged

> "Because they can't do anything else for me" (35,229).

Gordon had no will to progress, was not motivated to make decisions for himself and accepted what he was given. When Gordon was at home, in

Period Four, he seemed to have a little more insight into what he could do to help reduce his deterioration. Gordon thought he could still improve by

> "Getting up and walking" (39, 293-305).

However, Gordon still had no pre-functional or functional goals and no plans to do extra exercises to maintain or improve his function. Gordon's daughter thought Gordon would do exercises

> "Whenever he wants to" (39,360) and
> "Whenever it suits him" (39, 352).

The third position (Table 9.4), which demonstrates stronger involvement, was to move away from the acceptance of paternalistic decision-making. This was exemplified by Jack who discussed issues as if they were his responsibility much earlier than Joe. Additionally, unlike Joe, Jack's concept of rehabilitation was one of preparation for action as well as action. For example, where Joe discussed his exercises alone (above) Jack discussed pre-functional goals in terms of the extra stamina he needed to complete the exercises.

> "I've got to improve this still" (42, 284).
> "If I could just get more energy" (42,615).

The physiotherapist provided a paternalistic moderation to Jack's expectations of himself

> "Every time I [the physiotherapist] go to see him he will say "I'm so weak, I'm so weak" and I keep saying to him you've been really poorly but I think he is a bit hard on himself" (41, 108-111).

However, the physiotherapist did not direct Jack about his ideas to increase his stamina; these came from Jack.

Additionally, Jack, unlike Joe and Gordon, was able to learn from the staff and keep the focus of attention, and so the locus of control, on what he did and wanted rather than on a compliance with what the staff wanted him to do. In Period Two, when asked if Jack thought being responsible in his rehabilitation and care was important, Jack said

> "Oh I think so, I think so, I mean you are just like a lump of dead meat if you were sitting waiting on anyone to tell you do this do that, you know you have to get involved" (43, 617-620).

Jack also took a personal responsibility for the decision to come home because it would aid his progress.

> "I wanted to come home. Not just to be among my own things but I felt I could progress better by coming there and having to do things for myself" (49, 529-531).

This was different from Joe and Gordon, who similarly wanted to go home but had no plans to continue with rehabilitation *post*-discharge.

At home, Jack took more responsibility for himself than Joe or Gordon.

> "Yes it takes time and the showering, as I say, that's why I am in my dressing gown, it takes time in the morning to shower and dress, it probably takes me oh, about an hour and a half to shower and dress, whereas normally half an hour would have done that.... Like putting a pair of socks on is a major operation" (49, 541-547).
> "Everything is a struggle. To get up out of the chair, to have to think about every movement you make" (49, 62-66).

Jack took decisions about his progress and a personal responsibility for how this might be achieved, striking a balance between risk-taking, not wanting to fall over, as discussed above, and pushing the boundaries of his physical abilities seeking improvement. Jack said

> "It would be quite easy to lie back and do nothing, shout for people to come and help you but you have got to struggle out of the chair and

> you have got to, you know, try and do everything you can yourself washing and dressing and just moving in general” (49, 77-81).
>
> “Oh I think you have got to want to improve you know, otherwise you will be there for evermore. I think you must want to improve. You need to stretch yourself and, you know if you don’t try something even if you fail you try it again the second time you do [it] you know you can do it so you push on. You have to push on” (49, 618-628).

This third position (Table 9.4) was also taken by Josie, in some ways. Although different decisions were made, Josie also made personal decisions that were logically based, for example, the choice to go into a Nursing Home was not necessarily her preferred choice, but the best option.

> “I was going to need more care [than she needed prior to being admitted to the Intermediate Care unit] – possibly through the day – but I intended going home first and seeing how things worked out. But the longer I’ve stayed here and see the way I am, I know it’s a waste of time going home. Because I’m far better just go to the Nursing Home where I’m being looked after because by the time I pay this one and that one and the other one, it’s going to be costing me nearly as much money. And after all, it’s my quality of life I’ve got to think about” (24. 290-303).

Josie did not want to burden her family.

> “But I’m going just to have to accept it [going into the Nursing Home]. Because I wouldn’t go and live with any of the family. I wouldn’t put it onto anybody – I think it’s wrong. Everybody has got their own lives to lead. Plus I’m going to [Place], which is where most of my family live. I mean, they’re not brothers or sisters – they’re cousins and cousins’ families. But there’s plenty. We nearly all live in that surrounding area. So I’ll have plenty of people popping in to see me. In fact, I might get sick of them some of the time” (24, 314-326).

This was a hard decision for Josie as she needed people around (this will be discussed in chapter ten (Relationships). However, the people she needed most were prevented from helping her because Josie did not want to be a burden to them.

The input that the staff had into Josie's decision to move into a Nursing Home was not transparent. The staff nurse said

> "There was a discussion about whether Josie would go home for a while and have a large supportive care package or go to a Nursing Home" (25, 382-388).
>
> "But then it was decided that nursing care was the only option" (25, 391-396).

The staff nurse agreed with this decision.

> "I think if she knew that there was a different way that she could be more active, and it would produce different results, I think she... certainly I believe, able to do things differently, if she knew that the end result would be worth achieving. I think she now realised, or has got herself an imposed limitation on, what she is going to achieve now and has had for several weeks"[sic] (25, 757-768).

Other decisions that demonstrated this third position, and demonstrated that Josie had taken personal responsibility of the process of the move, occurred when Josie asked her cousin to view a room in a chosen Nursing Home and, on the basis of the report, asked her to secure it for her. Josie then began to plan how she would live in the Nursing Home and move from her own home. Josie said

> "[I] want to bring my telly down and wardrobe and drawers" (28, 533-534).
> "[I want to] put in my phone using the old phone number" (28, 534-537).
> "[I want to] leave the gas and electricity on at the old home planning that the house might not be sold by next winter" (28, 541-546).

The staff thought that Josie was capable of making decisions.

> "She is able to weigh up the pros and cons of staying and going home" (22, 68-70).

These decisions, made by Josie about her future care, demonstrate her strong involvement and differ markedly from Gordon, who did not make decisions, or take personal responsibility. Gordon did not try to take control of his future during, or after, his rehabilitation.

In some ways the achievement of Josie's goal to move into the Nursing Home and unattainable hopes about her impairments, equates to the achievement of Joe's goal to go home, in that when they achieved their goals, both had to start reappraising their lives again. In Jack and Gordon's case they both carried on the way they were in the Intermediate care unit but had very different outlooks. Jack's discharge facilitated his functional improvement through personal decision-making and taking personal responsibility and control in his home setting. Gordon's discharge facilitated the transfer of decision-making from the staff of the Intermediate Care unit to Gordon's daughter and the care staff employed to care for him.

Takes Steps to Reduce Risk

All the participants complied with the instructions of the staff, to a large extent, which reduced the risk of physical injury in the Intermediate Care unit. The differences in the participants' abilities and attitude towards risk management, which demonstrated different levels of involvement, were most clearly shown *post*-discharge and summarised in Table 9.5.

Table 9.5 A summary of how the Participants Reduced Risk

Risk Management Stance	**Joe**	**Josie**	**Gordon**	**Jack**
Takes personal steps to reduce risk	No	Yes (where possible)	No	Yes
Organises steps to be taken to reduce risk	No	Yes	No	Yes
Allows others to take steps to reduce risk	Yes	Yes	Yes	Yes
Accepts others advice to reduce risk against personal wishes	No	No	Yes	No
Level of involvement	Weak	Strong outside of physical function	Very Weak	Very Strong

The strongest involvement position was a demonstration of the ability to personally reduce risk or organise for risk to be reduced (Table 9.5). Jack was the only participant who demonstrated the ability to take steps to reduce risks by himself through his insights into how to stop himself falling. In this way, and in conjunction with the occupational therapist, Jack demonstrated a different level of involvement to Joe and Gordon. Where Joe relied on his partner and Gordon relied on his daughter and carers, Jack was able to use previous experience of rock climbing, with some versatility, to reduce the risk of falling as discussed in chapter eight (Cognitive Development). In addition, Jack planned to reduce the risk of falling in his flat further, in various ways, with the help of the occupational therapist. For example, Jack rejected a grab rail outside his home for aesthetic reasons. The occupational therapist said

> “I did advise a grab rail at that step, but he assured me that he could manage without, which he did really well, just holding onto the wall. And he is going to keep a stick in the corner so he can pick that up and use it to go into the bathroom” (47 107-114).

> “And then he is going to leave a Zimmer frame at the step so when he comes out he holds on to it and he steps down and he has got both hands on it which is very safe” (47 118-120).

Jack also demonstrated a different form of risk reduction by continuing to exercise, which is something that none of the other participants did or planned to do.

> “Oh, I have a lovely long passage and I can exercise. I can walk up and down there” (49, 249-254).

Josie’s circumstances made it difficult for her to take steps to reduce risk on her own. This was because, being bedfast, Josie was physically dependent on carers in a Nursing Home, who looked after her in a way that precluded personal risk-taking. Josie did not like this, demonstrating a desire for stronger involvement, which may have, in part, led to the despair Josie felt, discussed in chapter seven (Disposition).

Joe did take some steps to reduce risk, for example, by asking his partner to help him, pick things up from the floor.

> “I have to shout at her to get her if I drop this or drop that, well I can't get down to pick things up” (19, 219-221).

This showed the reliance Joe demonstrated in the Intermediate Care unit (Table 9.5). However, at the end of the data collection, Joe was waiting for the promised home alterations that would help him to progress and reduce risk, rather than working on, for example pre-functional and functional goals to help him to improve.

In summary, Jack made personal efforts to reduce risk and had the strongest involvement, while Gordon allowed risk decisions to be taken out of his hands and so had the weakest involvement. This differed from Joe, who was waiting for people to make decisions to help him to reduce risk and would be likely to be involved in actions that he was told to do in the future. Josie was so physically disabled that she had much less choice about the level of risk she was able to take in this new-to-her Nursing Home environment. However, Josie still tried to manage the risk within her environment

Manages Uncertainty

All the staff, particularly the physiotherapists, tried to reduce the risk of falls by, for example, having someone walk behind the participants with a chair when they were practicing walking. This was so that if the participant suddenly became weak or fainted, there would be opportunity to sit the participant down before he, or she, fell on the floor. However, within this, especially as they became stronger, the participants as a group adopted four positions on managing uncertainty, each demonstrating different levels of involvement. These positions were: Management by expression, either verbally or by action; management by trust, or tolerance; management by creating certainty out of uncertainty; and ignoring phenomena that might create uncertainty. These positions are summarised in Table 9.6.

Table 9.6 A Summary of how the Participants Managed Uncertainty

Managed Uncertainty...	**Joe**	**Josie**	**Gordon**	**Jack**
Through Expression				
a) Verbal	Yes	Sometimes	No	Yes
b) Personally Driven Action	No	Yes	No	Yes
At Home Through Action	Not substantially	A little	No	Yes
Through Trust or Tolerance	Yes	No	No	Yes/No
Through Creating Certainty out of Uncertainty	Yes at the beginning – No on discharge	Yes	Yes	No
Having Little to be Uncertain About	No	No	Yes	No
Level of Involvement	Quite weak	Apparently Strong but misaligned	Very weak	Very strong

Management by verbal expression and personally driven action (language and behavioural gestures) demonstrates the strongest involvement. Management by verbal expression was exemplified independently by Joe and Jack when they were uncertain that they would be allowed the time in the unit to recover sufficiently. They both managed this through asking the staff directly and so learned about how they would be managed, as discussed in chapters eight (Cognitive Development) and ten (Relationships). This equates to using “Voice” (Hirschman, 1970) as discussed in chapter two (Background). Jack also managed the uncertainty of the achievement of his goals, by taking personal responsibility and control for the amount of exercises he did to achieve his functional goals during his rehabilitation, and by building up his stamina.

The second position was to manage uncertainty through trust or toleration. Joe managed his uncertainty by following the lead of the practitioners and working hard at doing what he was told, trusting that if he did this he would be *allowed* to go home. Joe assumed that doing what he was told would lead to the achievement of his goals around independence, as discussed in chapter eight (Cognitive Development). Adopting this position Joe, achieved his goal of being discharged home and was functionally more able on discharge. However, Joe was not independent, being more reliant on his partner than he would have preferred. Some part of Joe wished that the alterations to his home, that would facilitate his mobility, especially outside, had been carried out prior to discharge as discussed **in** chapter eight (Cognitive Development).

A variation of this type of management of uncertainty, was the toleration of uncertainty until a later time, for example, Joe was uncertain about his ability to drive again, discussed in chapter seven (Disposition). At the end of the data collection period Joe was still wondering if he would improve enough to drive again. Overall, the level of involvement exemplified by Joe was of quite weak in this respect (Table 9.6).

A third position was the creation of certainty out of uncertainty, exemplified by Josie who, uncertain of her future, created a vision of how she would live in the Nursing Home, being mobile and having social outings as discussed in chapter six (Vision Incentive and Goals). These issues were not discussed with the staff and were probably part of the hope that inspired Josie during her rehabilitation stay. By working through others, Josie affirmed her developing relationships, which helped her to manage her uncertainty about how well she was liked by those around her. This position is one of apparently strong involvement, but in terms of Josie's functional goals was misaligned (Table 9.6).

The fourth, and last, position was not having any uncertainties and is a demonstration of a very weak involvement (Table 9.6). Gordon did not manage uncertainty through working hard under direction, like Joe, nor did he take charge of his own pathway to functional improvement, like Jack. Gordon was not trying to become functionally more able and was not hoping for something unattainable, unlike Josie. Gordon's position meant that he appeared to have no uncertainties about the length of time he might be allowed in the Intermediate Care unit and he did not look for functional progression. George was unconcerned about whether or not he would be cared for at home or in a Nursing Home. This weaker level of involvement was carried through to Gordon's position at home as he allowed his plans and routine to be changed by his daughter, in terms of his ability to get into bed on his own, and by the carers, who altered his bed time as discussed in chapter eight (Cognitive Development).

Conclusion

The management of risk and physical risk in particular, is an important part of rehabilitation. Initially, at the start of rehabilitation, the practitioners played a large role in risk management and for those participants most involved, the management was passed to the participants over time. This transition did not occur very much at all for one participant and conversely for another, his will to take risks, perhaps unwisely, was apparent to the staff. Inability to risk manage personally was also associated with an over reliance on the staff to make decisions. Additionally, especially for one participant who was physically incapacitated, risk was concerned with changing environments as well as the management of physical ability.

Chapter Ten: Relationships

Introduction

Relationships do not feature in the Involvement Attribute set. However, it is through relationships that the Involvement Attribute set operates. This chapter is concerned with the types of relationships that each of the participants developed with the staff of the Intermediate Care unit during their rehabilitation stay. These relationships changed over the rehabilitation period as the participants progressed in their rehabilitation and care. This is discussed in terms of the axial codes within the relationships category, which are: Reliance and Trust, Compliance, Added-value and Divergence, Asking for help and Works with Staff and Family towards Collaboration and Partnership. A summary of the constructions is provided at the end of this chapter.

Reliance and Trust

At the start of their rehabilitation the three participants who later improved functionally enough to go home, Joe, Gordon and Jack, were initially functionally reliant on the staff and were managed closely by the practitioners. Therefore the locus of control was very much with the staff of the Intermediate Care unit (Table 10.1) and involvement opportunities for the participants were reduced.

Table 10.1 A Summary of the Participants' attitude towards Reliance at the start of the rehabilitation (Period One)

	Joe	**Josie**	**Gordon**	**Jack**
Attitude towards reliance	Trusting, Accepting Interested compliant	Trusting Concerned Interested	Trusting Accepting Not interested	Trusting Tolerant Very interested
Locus of control	With the staff	With the staff	With the staff	With the staff
Level of Involvement	Weak but Apparently strong	Moderately strong socially	Weak	Strong

The physiotherapist stated that the participants had been told at the start of their rehabilitation that they were not allowed to do anything physically on their own in order to reduce the risk of falls. This instruction was part of the physiotherapists' risk management strategy, given at a time when the participants were physically weak and was expressed, by the physiotherapist about Jack.

> "I think he'll probably wait for us to say he's safe, really, rather than doing it himself. I think it's the right thing to do because we've said to them initially right you need to have somebody with you when you are walking so I think they kind of wait for us to say right it's okay now. So quite a lot of people just do it on their own, but I haven't seen Jack and I think it is a confidence issue with him as well" (44, 137-157).

However, even at the early stages of rehabilitation, there were indications that the participants differed depending on their attitude towards reliance which varied from acceptance to tolerance (Table 10.1).

Strong functional reliance and trust, which demonstrated weaker involvement, was exemplified when Joe described his medications in Period One. Joe said

> “Well there is about 5 there but what the other ones are for I don’t know. I’m not gened up enough (don’t know enough) er and I’ve never asked them. I never query what er.. They’ll be poisoning me as far as I know but I’m none the wiser” (11, 501-506).

Jack had a similar reliance and trust, but differed from Joe in that Jack realised his reliance on other people had increased, and tolerated this (Table **10.1).**

> “Well you have to (change) you have to, you know, change your attitude and let them do things or you will be struggling all the time” (40, 265-267).

Initially, Gordon was physically reliant in similar ways to Joe and Jack, but had no desire to do things for himself.

> “I just do what they tell us to do” (30,355).

Josie was concerned about her reliance but was told to accept the situation (Table 10.1).

> **“**Because, as one of them said to me, remember this – if anybody ever says anything to you, all you’ve got to say to them is if you didn’t have me like this, you wouldn’t have a job. Which is right” (20, 575-580).

As the rehabilitation progressed the level and type of reliance on, and trust in, the health care staff and themselves, began to diverge (Table 10.2).

Table 10.2 A Summary of the Participants' attitude towards Reliance in Periods Two and Three

	Joe	**Josie**	**Gordon**	**Jack**
Attitude towards reliance	Trusting, Accepting Of the system and processes set by the staff. Interested	Concerned and interested in her care, organising others and herself Sometimes reliant on staff for mood level	Trusting Accepting Not interested	Self-reliant Interested
Level of Involvement	Apparently strong but falling	Strong socially, weak physically	Weak	Strong
Locus of control	With the staff	Overall, Moved towards Josie	With the staff	Moved towards Jack

Firstly, there was a reliance and trust in the system without overt consideration of the processes within the system (Table 10.2). For example, Joe was concerned about being able to go home, and continued to rely and trust the practitioners to make the decisions about physiotherapy into Period Three.

> "I just do as I'm told like a little schoolboy" (16, 184-185).

In this type of reliance and trust Joe was not focussed on what he could be doing for himself. The locus of control remained with the practitioners. Joe thought he could achieve his social participation of going home, through hard work and a strategic reliance on the health care staff, as a passive receiver of rehabilitation and care.

> “I’m willing to try anything. It’s the only way I’m going to get out of here” (5, 27).

An increased level of involvement was also demonstrated by a requirement for reassurance at this stage. An example of this was when Joe required reassurance that he would be able to stay in the Intermediate Care unit long enough for him to improve.

> “Well I asked. I asked the physio. I says, When do you give it... when do you say right enough is enough we cannot do no more. Well it’s reviewed after six weeks .We have a meeting amongst we’ selves and say why he’s going to get no better we cannot do no more for him she says but 9 times out of ten we say six weeks but if we think there is improvement as you are going up and above this six weeks, we will keep you ya know trying like” (10, 270-281).

A second position was a reduction in the level of reliance and trust in the staff as the rehabilitation progressed (Table 10.2). Jack’s reliance on, and trust in, himself increased markedly during rehabilitation indicating stronger involvement.   When asked which Jack preferred, people to do things for him or to do it himself, he clearly associated doing things for himself with his personal development on the rehabilitation pathway. Jack said

> “Oh I think so, I think so, I mean you are just like a lump of dead meat if you were sitting waiting on anyone to tell you do this, do that, you know you have to get involved” (43, 617-620).

As Jack progressed towards functional independence, he was able to demonstrate a trust in himself rather than others. This was demonstrated by

Jack being able to make suggestions to the staff and moved the locus of control towards him.

> “I don’t know if I have any involvement. I have the physiotherapy and the kind of thing that concerns me like this left leg and this artificial knee. They listen; I don’t know if they take it in or not but I’m sure they listen” (43, 554-558).

Another development was to fail to become more involved and self-reliant over time. Gordon did not have strong goals at any of the four levels, so he did not need to trust the health care staff to facilitate him to any particular functional level (Table 10.2). Gordon did not have to rely on himself, or the staff, as he was confident of the assistance of his daughter at home.

> **“So who prepares that [your meal] for you?**
> My daughter.
> **Does she ever do anything different now that she did before you went in [the Intermediate Care unit]?**
> No.
> **Is it exactly the same?**
> She gets my tablets right” (34, 81-88).

The failure to become more self-reliant, during the rehabilitation stay, led to the physiotherapist thinking Gordon may deteriorate after the rehabilitation period.

> “It’s basically because I’m just worried that when he (Gordon) goes home he is going to get into that chair and he’s just going to sit there.” (38, 161-163)

Josie exhibited two of the above types of reliance and trust (Table 10.2). In some ways the locus of control remained with Josie. She trusted herself to organise the staff to make sure she was comfortable and safe. Examples of this are Josie’s conversations with support workers and nurses about the position of her bed table, as discussed in chapter eight (Cognitive

Development). In other ways, Josie's reliance and trust was like that of Joe, where the locus of control was with the staff, uncritical and centred on her personal comfort and wellbeing. This was demonstrated by Josie's acceptance of her carers' instruction to accept her dependence, described in this chapter.

Josie also exhibited a different type of psychological reliance concerned with her mood, where the locus of control was positioned with the staff, and which demonstrated a weaker involvement (Table 10.2). Although Josie had an outgoing personality, she was sometimes reliant on the staff to keep her spirits up and her mood altered, sometimes over short periods of time.

> "We have got to know Josie lately. Where you know, of late, where, where you just look at her and she is quite down. But if you have, what we would call, if you have a bit of daft carry on with Josie, if you try and buoy her up before you do any work with Josie, before you do any work with her at all, any personal hygiene tasks anything, if you sort of gee her up and buoy her up into a better frame of mind she is more receptive and it sets her up for at least an hour or two during the day you know" (23, 313-326).

Compliance, Added-value and Divergence

Compliance is important in rehabilitation, especially as a risk management tool in the early stages of rehabilitation. However, at varying points in the rehabilitation stay, the compliance of the participants began to change in nature. These changes in nature occurred when those who were most involved in their rehabilitation began to add value to the rehabilitation work they were doing and began to express personal ideas and actions (divergence) that moved them away from early paternalistic relationships.

This added-value and divergence moved the locus of control towards the participants.

Compliance

The level of compliance was on a continuum concerned with the length of time the participant had been in the Intermediate Care unit and their attitude towards compliance. This relates to the level of Involvement (Table 10.3). Demonstrating the weakest involvement, compliance took the form of allowing the staff to care, making little effort in rehabilitation outside of formal physiotherapy sessions, adding little value and demonstrating little divergence from doing only what they were told to do. This positioned the locus of control away from the participant (Table 10.3) and was exemplified by Gordon.

Gordon was compliant to all the wishes of the staff but had to be encouraged to do his functional exercises. Gordon was also compliant with the care he was provided, participating by request. This was demonstrated by the nurses, who felt that he would let them care for him, as discussed in chapter seven (Disposition).

Table 10.3 The Levels of Compliance and the Locus of Control, with examples

	Joe	**Josie**	**Gordon**	**Jack**
Compliance	High, eager	High but moderated	High, passive	High but moderated
Locus of Control	Usually towards the practitioners Exceptionally asked for a Zimmer frame instead of a wheelchair on offer	Towards Josie socially, towards the staff physically	Heavily towards the practitioners	Towards Jack
Examples	Usually complied with the regime eagerly and followed instructions	Modified the regime by organising her environment to suit herself. Made decisions about her care	Complied with the regime participating by request	Modified the regime by organising extra food he liked in a systematic way and doing extra exercises
Level of Involvement	Apparently Strong	Strong socially and physically	Weak	Strong

At the next level, (Table 10.3) the participants were keen to do what they were told but added some value to the rehabilitation and care work. However this was not significant enough to move the locus of control away from the staff. The level of involvement was only apparently strong. Joe exemplified this position. Joe was eager to do what he was told throughout his stay in the Intermediate Care unit. However, he did not question the staff appropriately. For example, in Period Three, Joe was expecting to be able to go home after a review of his progress. Although Joe was not told anything about the details of the review (which took place each week), Joe stated

> “I mustn’t have come up to their standards” (16, 410-411).

Joe did not receive the news he wanted, but was not concerned about the reasons for this.

At a third level of compliance, High, (Table 10.3), participants were able to use the rehabilitation system to achieve their own aims and, where the system did not meet their needs, they were the most successful in making the changes they needed. At these times the level of compliance remained high but the participants’ added significant value to the rehabilitation and care regimes, and the locus of control, moved towards them. This was demonstrated by Jack, who asked his wife to bring in extra food to help to build up his stamina

> “I’ve got to improve this still” (42, 284).
>
> “If I could just get more energy” (42,615).

This position was also occupied by Josie who in her care added significant value to the care regime. This was discussed in chapter nine (Risk Management).

Added-value

For those participants who demonstrated added-value (Table 10.4), there were two main ways they did this within the rehabilitation and care regime. Firstly psychologically, by reflecting on the work they were doing to see how this could be improved (discussed in chapter eight (Cognitive Development), and secondly actively, by working on their own without direction and instruction. Both these ways demonstrated stronger involvement and, where absent, weaker involvement.

Table 10.4 The Levels of Added-value, Responsibility and Decision making, and the Locus of Control, with Examples

Participant	**Joe**	**Josie**	**Gordon**	**Jack**
Added-value	Moderate	High	Very low	High
Personal Responsibility	Low	High	Very low	High
Decision-making	Low	High	Very Low	High
Locus of Control	Towards the practitioners	Towards Josie	Heavily towards the practitioners	Towards Jack
Examples	Made decisions to do more in his care and took some responsibility for extra exercises	Organised her environment in the Intermediate Care unit to suit herself. Made decisions about her care	Did not add value to his rehabilitation or care regime, took little responsibility and made no decisions	Took staff's instructions as advice. Worked on his own pathway

Gordon added very little value to the rehabilitation or care regime (Table 10.4). For example, Gordon did not ask for more physiotherapy. When asked if he would ever ask for more physiotherapy he said

> "No, I just leave it to them. They should know whether they could do it or not... if they've got the time" (30, 319-321).

When asked if she thought Gordon minded being directed, the physiotherapist said

> "No not at all. No I think he wants to be directed (38, 211)
> "I felt like a lot of the time with Gordon I was trying to push him... I tried not to be very negative with Gordon because I didn't feel like that

> was a good tack to take with him. I always try to be more positive" (38, 406-411).

In this instance the physiotherapist was trying to encourage some enthusiasm. The physiotherapist realised that when Gordon left the Intermediate Care unit, this direction and drive would be absent.

> "When Gordon goes home and hasn't got someone to drive him in his physiotherapy he will deteriorate" (38, 41-414).

Jack did add value to the rehabilitation through learning and through action (Table 10.4). Jack did his exercises because he wanted to do them; he was on his own rehabilitation pathway using the practitioners as a resource. This was demonstrated by Jack's attitude towards extra exercises.

> "Well I usually go to the gym in the morning for physiotherapy and then in the afternoon I lie on the bed and try to do a few extra. I can sit in the chair here and I've got other exercises to do as well" (43, 45-52).
>
> "In the chair "I have to raise a foot" (43, 56-65).

Jack demonstrated what he needed to do by raising his leg straight out and then bending his leg at the knee. He repeated the exercise with his other leg.

> "Yes well I sometimes… I lie on the bed cos I can do exercises to strengthen my thighs" (43, 13-14).
> "I tense my thigh and press down on the bed and then raise my foot" (43, 22-27).

Joe also added value to the rehabilitation regime (Table 10.4), but in a different way. He did take some personal responsibility for his physiotherapy by exercising in his own room, but this was when directed and instructed to do so by the physiotherapist.

> “Well I do them every hour. Every hour I do them maybe 10 leg movements 5 times. I get up and down 10 times every 20 minutes. I couldn’t do it continuously it’s very tiring but it’s ok if you don’t sicken yourself. When you feel a bit bored do it” (14, 10-13).

This was verified by the physiotherapist

> “When I went along today he has got it there under his legs and he said I’m just having a rest and he had already been doing the exercises” (15, 24-27).

Therefore Joe’s added-value was not self-directed. Joe was not making extra exercises a high priority and did his exercises when he was bored. Joe was not adding value through learning about the process of rehabilitation and thinking of the incremental functional improvements this might bring. He claimed, repeatedly, that his lack of knowledge prevented him becoming involved in decision-making. This weakened Joe’s involvement.

> **“What was your level of involvement with your care do you think?”**
> “Well nothing really like, I left everything to them. I cannot… I couldn't really tell them what I wanted done” (Period four interview).
> **“Did you feel you wanted to tell them anything?”**
> “No not really no. As I said they were all dedicated people like and erm... they seem to know what they were doing” (19, 178-183).

Josie was not able to add value to her rehabilitation in the same way as the other participants. However she did add value to her care regime as discussed under “Seeks Personal Solutions to Progression Barriers” in chapter eight (Cognitive Development).

Divergence

The participants were not always absolutely compliant with the often paternalistic management system provided for them, especially towards the end of their rehabilitation. Examples of divergence from the paternalistic direction of staff were interpreted as times when the participants were thinking for themselves, and so were more involved within these relationships. Examples of Divergence are summarised in Table 10.5.

Table 10.5 Levels of Divergence and the Locus of Control

Participant	**Joe**	**Josie**	**Gordon**	**Jack**
Divergence	Quite Low	Moderate where possible	Very Low	Moderate
Locus of Control	Mostly towards the practitioners	Towards Josie in none-care areas	Heavily towards the practitioners	Towards Jack
Acceptance of Paternalism	High	Low	Very High	Low
Examples	Did not want to take analgesia that was very strong	Organised her environment collaboratively where possible. Made her own decisions	Complied with the regime participating by request	Complied with the regime, but made his own decisions

Joe was not entirely compliant with his management in the Intermediate Care unit and there was some evidence of divergence. For example, about physiotherapy equipment the physiotherapist said

> “Equipment wise, erm, there’s not much extra that Joe could do” (15, 243-244)

Joe did not agree with this and in Period Four, discussed the use of a cycle and treadmill.

> “I think they could do with a bit more facilities in there like, erm. They are very limited with what they’ve got” (19, 407-410).

Joe was suggesting that he might have progressed further in physiotherapy if he had been able to use better equipment.

> “Well I think a bike, you know, a static bike. They've only got a pair of pedals. We could have done with a treadmill or something, erm something like that. But as I say, you know, they got us the arm pulls and a few stairs to go up and the parallel bars. You know that is very limited of what they... what they can do I think, personally” (19, 312-316).

Joe did not mention this to the physiotherapist at the time, but in Period Four, at home, he was looking for resources, external to him, to help him progress and demonstrated he had not managed a partnership relationship with the staff.

Another sign of divergence was the increasing use of resources by choice, over time. Joe was focussed on his functional improvements and two specific examples, the use of a Zimmer frame and in shaving, demonstrate his reduction in functional dependency. In each case, Joe chose or thought of alternatives to the prescribed action proposed by his carers. Firstly, Joe chose to use a Zimmer frame instead of being wheeled around in a chair by the care staff.

> “It just happened one night. They says should I get the chair? I says oh give us a go of the Zimmer and so since then I’ve just been using that like” (16, 69-72).

Secondly, Joe started to shave himself again

> “In here the lasses generally shaves us. I says, Oh, give me a go. So I shaved myself yesterday like” (16, 332-334).

These developments towards independence did not happen to Gordon who remained dependent on the care staff through rehabilitation.

> "But he does, you know, let you do things for him. He's quite happy for you to do things for him so I don't know whether he would say "Let me do that." I think he would just let us do it" (34, 108-113).

Although Jack was compliant with the staff, he was able to say what he wanted and to make suggestions. Jack's attitude was similar to that of Josie as they were both able to organise things to make themselves comfortable, safe and create a position from which they could achieve their goals in the Intermediate Care unit.

At home, Jack made decisions about how much risk to take. The occupational therapist hoped that Jack would accept his limitations, but it was Jack who was trying to decide what those limitations were going to be. Jack continued to learn and take control of his own rehabilitation pathway. The occupational therapist thought that it was possible that Jack could improve at home; she rated his risk of falling outside at 10/10 and hoped he would begin to accept his limitations, as discussed in chapter nine (Risk Management).

Asking for Help

Each of the participants demonstrated a different level of involvement through the way they approached the staff for help and their rationale for this. There were three main types of approach, which demonstrated the different ways the participants were involved in their rehabilitation and care (Table 10.6).

Table 10.6 A Summary of Three Different Ways the Participants Asked for Help Related to the Level of Involvement and Outcomes

	1	**2**	**3**
Different Approaches to Asking for Help	Asked for very little	Did not like to bother the staff unless it was important	Always asked the staff to meet needs as a method of controlling the environment or helping in rehabilitation
Level of Involvement	Weak	Moderately strong	Strong
Outcome at the end of the research	Unconcerned	Was unsure about the future, perplexed	Used the same techniques described above in the Nursing Home or at home
Participant	Gordon	Joe	Jack and Josie

Sometimes the participants refrained from asking for help unless it was very important. In this case the participant would wait for a member of staff. This was exemplified by Joe, who made few personal demands on the staff and who showed his deference to a system on which he was reliant.

> "No I never ring them no I kna [know] they're very busy when they have a full ward I just wait until they bring them or ought like that. The only time I ring them is when my bottle needs emptied... ya kna" (1, 452-456).

This weakened Joe's involvement in his rehabilitation. However, when it was very important, in a functional way, Joe did ask for help and managed to obtain his own way. For example, when Joe wanted to lay on his bed, the nurses would not help him on to it and initially Joe had to make a "fuss" about wanting to lie on his bed. The nurses wanted him to sit in his chair in the morning, after breakfast, but Joe was uncomfortable and preferred to lie on the bed.

> **"So they did put you on top of your bed this morning?"**
> "After a bit of persuasion, well a bit of a moan" (11 460-475).

As Joe became able to get on and off his bed he no longer needed the carers help and so did not ask permission.

The second approach was to ask for very little, even when the staff were present. Gordon had seemingly minimal needs and did not ask the staff for many things when others were prepared to ask. For example, Jack, who had strong goals to improve functionally, asked for more physiotherapy and did extra physiotherapy systematically but Gordon did not ask for more physiotherapy and the goal to leave the Intermediate care unit more functionally able, was less clear.

> "He never asks for more physiotherapy or to do anything different in the gym" (38, 105-111).

This weakened Gordon's involvement in his rehabilitation.

Gordon's attitude to his rehabilitation was similar to that of Joe, in some ways, in that he relied on the physiotherapists to tell him what to do. However it became clear that Gordon did not have a clear goal to try to become as independent as possible, as discussed in chapter six (Vision, Incentive and Goals). When this was discussed with Gordon's physiotherapist she stated that

> "He has to be prompted to ask, you know, is this OK? Is this what you want to do? Is this still your end goal? And I think, you know, when

> you prompt them obviously he will respond but I don't think Gordon would actually be somebody who, at the moment, would actually state this is what I want, you know x,y and z" (33,187-192)

Although Gordon espoused that he wanted to go home to do some gardening and to be in his own surroundings, in the relationships with the staff, these goals were not important. For example, when Gordon was in the physiotherapy room he waited to be told what to do rather than taking the initiative to start on his own (33, 164-166). The physiotherapist said

> "There is little response from him [when praise is given]" (38, 101-103).

A third approach was to ask the staff for those things that would help with further rehabilitation. This demonstrated the increased involvement that Jack had in his rehabilitation, above that of Joe and Gordon.

> "And I'm trying to boost my food intake with varying my diet a wee bit from the hospital diet which is a bit bland so (name), my wife, brings in bits of things to supplement my diet. And I eat small, but regularly, even during the night. I usually end up having a banana about 2'clock in the morning" (42, 619-628).

Josie was also quite capable of asking others to help her organise her bed space in a similar way that Jack was able to ask for help, and contrasts strongly with Joe and Gordon who often did not want to bother the staff.

> "I get them to leave these here [on the bed table] so I've got that for my bed. An' I've got this one for my buzzer so I'm alright" (26, 876-879).

When Josie spoke of asking the staff to do things she discussed it in terms of what she had organised.

> "I've got one or two of them who go to ward [name] and pinch us some ice cos we haven't got ice on this ward" (26, 967-969).

Works with Staff Towards Collaboration and Partnership.

Initially, all the participants had to come to terms with being cared for as they were unable to do some things for themselves. The participants' relationships with the staff demonstrate the different ways the participants perceived this care and their different levels of personal involvement (Table 10.7 Period One).

Three of the participants were embarrassed about being cared for in intimate ways but this embarrassment subsided as the paternalism from the staff was accepted. For example, Josie was embarrassed and concerned about

> "Doing your business in bed" (20, 561-562).

She was also surprised about the way she was cared for in intimate ways, for example by male nurses. However, Josie became used to this.

> "All my embarrassment and that has just... my modesty has all just gone. But you can't help it" (20, 858-865).

Although Josie was initially surprised and concerned, she learned to accept this, which weakened her involvement as the locus of control moved away from her.

Table 10.7 A Summary of the Types of Relationship, the Participants' Reaction to this and Level of Involvement During and After Rehabilitation

Rehabilitation	**Period 1**	**Period 2**	**Period 3**	**Period 4**
Participant	**Main approach**	**Main approach**	**Main approach**	
Gordon	**Paternalism**	**Paternalism**	**Paternalism** **Compensation and Decision-making by staff**	
Reaction	Passive acceptance	Passive Acceptance	Passive acceptance	Unconcerned still reliant on others
Involvement	Weak	Weak	Weak	
Josie	**Paternalism**	**Collaboration and Partnership**	**Collaboration** **Partnership**	
Reaction	Surprise, concern Acceptance	Discussions, organisation, "Friendships"	Discussions, "Friendships"	Reappraisal of position and potential Despair
Involvement	Strong (learning)	Strong	Strong	
Jack	**Paternalism**	**Collaboration**	**Partnership**	
Reaction	Conditional Acceptance (tolerance)	Makes suggestions, feelings of responsibility,	Taking responsibility, listening and discussion	Moving on with his own rehabilitation
Involvement	Strong (learning)	Strong	Strong	
Joe	**Paternalism**	**Paternalism**	**Paternalism**	
Reaction	Surprise Embracing acceptance	Acceptance in physiotherapy. Less so in care.	Moderate acceptance	Reappraisal of his position.
Involvement	Apparently Strong	Apparently Strong	Weaker	Perplexed

Another reaction to this type of care was to understand that the care was needed and to, temporarily, tolerate the paternalistic care delivered in this way. Jack accepted the care, conditionally, so that he did not have to struggle. Jack and Josie gave something up during this part of their rehabilitation stay, learning to accept the paternalism of the care delivery (Table 10.7 Period One). This demonstrated tolerance as discussed under Reliance and Trust in this chapter.

Another position was to accept the care as a matter of course without embarrassment. Gordon did not seem to mind strangers washing him. This may have been because he was used to his daughter doing this for him.

> "Oh I don't mind [nurses washing him]" (30, 153).
> "It's got to be done and that's it" (30 307).

Gordon was therefore different from the other participants in accepting paternalistic care without concern and demonstrated weaker involvement. These positions are summarised in Table 10.7 under Period One.

After this initial period of higher levels of care, three of the participants developed functionally and the relationships with the staff had an opportunity to develop towards collaboration and partnership within rehabilitation which would strengthen their involvement. The participants took one of four positions, summarised in Table 10.7 (Periods Two and Three).

The first position was continued acceptance of the paternalism.
The staff nurse said of Gordon

> "If he'd been unhappy I think he might have said something. But I think he's quite happy with what he's been given and getting so I don't think he would vocalise any more. You know I think he's accepted

> you know that we've got him to the stage he's at and he's happy with that" (34, 203-206).

It is interesting, in this last statement, that the nurse gives the credit for Gordon's improvement to the staff, "we", and not to Gordon himself, or collaboration between Gordon and the staff. This depicts Gordon as willing to be led through his rehabilitation, paternalistically, as a passive participant in a staff-orientated service with the locus of control with the staff. Gordon may not have been personally involved because he knew he could fall back on the services of his daughter and, in Period Two did mention that he expected Gordon's daughter to wash and dress him when he left the Intermediate Care unit.

> **"Do you think you're going to have any struggles when you get home?**
> No, not really.
> **What about getting washed and dressed?**
> "Well my daughter gets me washed and dressed" (33, 111-118).

This facilitated Gordon's subordinate, passive relationship with the staff and weakened his involvement in his care, which did not change during the rehabilitation period. Gordon allowed the practitioners to set his goals throughout his rehabilitation stay, which also weakened his involvement. The nurses seemed to want to do things for Gordon and developed a caring, dependent relationship with them, rather than a rehabilitation relationship.

> "I think because, you know, he's in hospital and that's what nurses and carers... and that's what we do. And I think sometimes we forget and automatically, when you've been doing something for somebody for such a long time you automatically do it and forget how much they can do. You just do it because you're on the ... you know on the role of getting everything sorted for them" (34, 58-64).

> "You know we're automatically... we might get his clothes out for him" (34, 46-47).

The staff nurse did not talk as if she was part of the rehabilitation team. Her relationship was that of a paternalistic carer. The staff nurse thought that if Gordon trusted the staff to lead his rehabilitation that would give him the confidence he needed.

> "[Gordon] trusts the staff to lead his... to lead his progress and he has moved on and motivated himself, a little bit, through that" (34-97-100).

If Gordon had been less passive, and less accepting of paternalistic relationships, he might have taken more responsibility for his functional abilities and taken more personal control at home so that he could go to bed on his own, and his bed time would not have been changed.

Because of Gordon's lack of involvement in the rehabilitation process, the physiotherapists kept the locus of control and became concerned, in a paternalistic way that Gordon would deteriorate once away from specific direction. In Period Four, Gordon was referred to the community rehabilitation team who would carry on his rehabilitation in his own home *post*-discharge from the Intermediate Care unit.

> "I'm going to arrange for him (Gordon) to have community physio. So hopefully that will help." (38, 135-136)

This may not have been necessary if Gordon had taken more personal control of the maintenance and development of his functional ability within his relationships with the staff and was further evidence of reduced involvement.

The second position was a variation of this paternalistic relationship and occurred with Joe. Early dependent relationships gave way to more functional independence whilst Joe remained cognitively dependent on the staff. However, unlike Gordon, Joe was not functionally passive. When the physiotherapist and occupational therapist saw Joe working hard at his physiotherapy during these periods, they did not seem to take into account that, when he was doing exercises in rehabilitation, he was primarily carrying out prescriptions, pleasing the staff and not achieving goals for his own sake. Instead of focussing on the day ahead and his own progress, self-appraisal and a more collaborative relationship with the staff that could help him achieve his goals, Joe's focus was on an uncertain time in the future when he could be told he could go home. Joe did not own the challenges of the process of his rehabilitation and his cognitively dependent relationship precluded his development in that direction and weakened his real level of involvement in his rehabilitation (Table 10.7 Period Three). The physiotherapist said of Joe.

> "I mean he's, he's progressed so much, erm, we, just kind of really, more or less, getting to the last stage of his rehab. now which is obviously the really important stage. Erm, I feel like he, he needs now to have really clear goals. To know that, right this is what we're doing and I think if we can get the access to the house sorted and get him seeing that we are nearly at the end, you know, it will really spur him on a bit" (17, 338-339).

The physiotherapist was saying that if Joe could own some clear goals again, his enthusiasm for rehabilitation would return and, in discussing the home alterations, was attempting to strengthen Joe's vision for the future. The physiotherapist was compensating for Joe's loss of enthusiasm and further demonstrates Joe's cognitive dependent relationship. This type of compensation reduced opportunities for collaboration and its acceptance weakened Joe's involvement.

In Period Two, Joe's goals were changed paternalistically from going home able to function independently, to managing at home safely, as discussed in chapter seven (Disposition).

> "Yeah, he was really independent (before hospitalisation) so ultimately that is what you always hope to achieve but we... but realistically we mightn't achieve that but, or what I will do with Joe I feel that one of our... our biggest aim really is to get him home, safely" (15, 196-203).
>
> "Once Joe is home safely new goals will be set by the community physiotherapy team" (15, 208).

This service was not offered on discharge.

Joe was not part of discussions that led to this decision about the change in goals but complied with the change, trusting the physiotherapist's judgement and his aim to go home. The effect of this change was that Joe was discharged more dependent on his partner than prior to his acute illness. Joe was aware of this and that it was against his earlier stated aims as discussed in chapter six (Vision Incentive and Goals).

If Joe had trusted less he might have felt he had rights within this relationship and protested, firstly, against the change of goals paternalistically imposed upon him, and secondly, that the promised home alterations were not ready prior to his discharge. If Joe had developed a more collaborative relationship with the physiotherapists he might have tried to secure the community service he was offered in the Intermediate Care unit. Joe did not do this and felt let down after discharge, firstly because the home alterations had not been carried out prior to his discharge, and secondly, because Joe's source of strength, in the form of the motivation and direction from the physiotherapists, had been removed. Joe still needed the directive relationship provided by the practitioners after discharge.

> "And er, just keep on, maybe come back for more physio here daily or weekly or whatever but to the best of my ability I want to go home" (16, 556-560).

However, Joe did not discuss this (expression) and took no action: evidence that he took little personal control which weakened his involvement.

Joe's relationship with the care staff seemed to develop more collaboratively than with the physiotherapists, perhaps because they did not take as strong a lead as the physiotherapists, who behaved more paternalistically. When Joe felt able to do some things for himself he took the opportunity, for example, to use a stick instead of a wheelchair and he chose to shave himself and, in doing so, strengthened his involvement, discussed earlier in this chapter (Table 10.7, Period Two).

The third position (Table 10.7) demonstrates the development of a stronger involvement and is an early recognition of an independent role for the participant within the relationships with the staff. Jack recognised that he had an independent role to play and that he was developing different relationships with different staff.

> "Some want to do too much for you, whereas some stand off and try to get you to do more for yourself" (40, 304-307).

When asked which Jack preferred, people to do things for him or to do it himself, he clearly associated doing things for himself with his personal development in his rehabilitation pathway which strengthened his involvement in his rehabilitation and care. Jack said

> "Oh to do things for myself otherwise I'm never going to advance" (40, 315).

This recognition of an independent role helped Jack to move towards collaborative and partnership relationships with the physiotherapists.

> "You have got to be able to suggest things to the physiotherapists and they are very willing and able to listen you know, adapt" (46, 358-360).
>
> "You are as much responsible as the therapists and others to carry out your part of the bargain" (46, 596-597).

Jack also moved towards a collaborative, partnership relationship with some of the nurses and support workers, and in doing so demonstrated stronger involvement. In Period Two Jack stated that

> "I used to think I had to ask for it [permission] but now I tell them what I want to do" (43, 445-446).

The last type of relationship (Table 10.7) was that which included elements of friendship.

Josie built up friendly relationships with those who cared for her, as discussed in chapter seven (Disposition), Josie liked

> "Just making so many friends with the staff and what not" (20, 549-550).

The staff also seemed to respond to Josie in the same way. In Period Two a support worker said

> “I personally believe in, and I think I build up a trusting relationship with Josie I think because it's done at her level it's done at her pace and it's done how she dictates, how she dictates, you know, it's on her terms” (23, 736-742).

In Period Three a staff nurse said

> “She is the kind of amiable person that you can’t help but respond to.” (27, 106-107)
>
> “She is very knowledgeable, and there is not many subjects that we’ve talked about that she doesn’t know anything about” (23, 498-505).

Josie was reliant on having a friendly relationship with the care staff. She stated that these were her only relationships.

> “Well, it’s not just with the staff really. I mean, there’s only the staff and my family that I got to talk to, you know what I mean” (29, 440-442).

Josie wanted, and needed, reassurance within these friendly relationships with the different individuals who cared for her, in a similar way that Joe and Jack needed reassurance discussed in this chapter. Josie increased her involvement within these informal relationships, acquiring information and organising her environment in the Intermediate Care unit. Josie also worked with her cousin to help her to organise her move into the Nursing Home, as discussed in chapter eight (Cognitive Development). In this way, like Jack, Josie took personal control and created her own pathway out of the Intermediate Care unit within collaborative relationships. However, unlike for Jack, there was no formal pathway for Josie, given the misalignment of her covert goals to walk again, discussed in chapter six (Vision, Incentive and Goals).

Jack, Joe and Gordon were reliant on a system that was designed to help them to maximum independence, and the overall paternalistic approach by the staff reflected that design. Although Josie was not going to improve functionally, the default approach by the staff was also paternalistic. However, Josie developed have some collaborative interchanges with some of the support workers.

Discussing these collaborative interchanges with Josie, she thought she was working with the staff and in doing so hinted that her relationships were partnership-based.

> "It's important really but I've got them into my way of thinking now as well as I'm into their way. Do you know what I mean?" (26, 1417-1421).

This was corroborated. When discussing Josie's participation with a staff nurse, the staff nurse said that outside of physical ability, Josie was able to discuss issues with the staff and ask for things to meet her needs in the same way that Jack did.

> "She has a mouth and she's not frightened to use it she, kind of, does that for herself" (27, 146-147).

Josie, unlike Gordon, also took an interest in, and planned for, her care as discussed in chapter eight (Cognitive Development). This partnership, working outside of physical functioning and rehabilitation, continued with the staff in the Nursing Home and was demonstrated when Josie was unsure when she was going to have her bed bath each day. Josie worked with the staff to be bed bathed by the night staff at 7am each morning as discussed in chapter eight (Cognitive Development).

Conclusion

For those with stronger involvement, initial paternalistic relationships, where decisions were made by the staff, gave way to more collaborative relationships, where decisions were shared with the staff and made independently. Weaker involvement, either generally or for specific issues such as particular aspects of care was demonstrated where opportunities for decisions to be made by the participants were not taken or were not able to be taken.

Conclusion to the Constructions

This section uses the analyses of the constructions to provide a conceptual understanding of Involvement in rehabilitation which explains the involvement of the participants in terms of the constructions and demonstrates the Theory of Involvement.

A Conceptual Understanding of Involvement in Rehabilitation

This section serves two purposes: firstly, to demonstrate how the Involvement Attributes work together to explain involvement in rehabilitation and secondly, to demonstrate this explanation in the constructions of the participants.

The Interdependent Provinces of Involvement

Considering an individual first, Involvement operates through an Involvement Attribute set which can be divided into two aligned groups.

1. Psychologically-based Involvement Attributes, (Vision and Incentive, Disposition (hope, motivation and enthusiasm) and Cognitive Development) and Goals (planning).

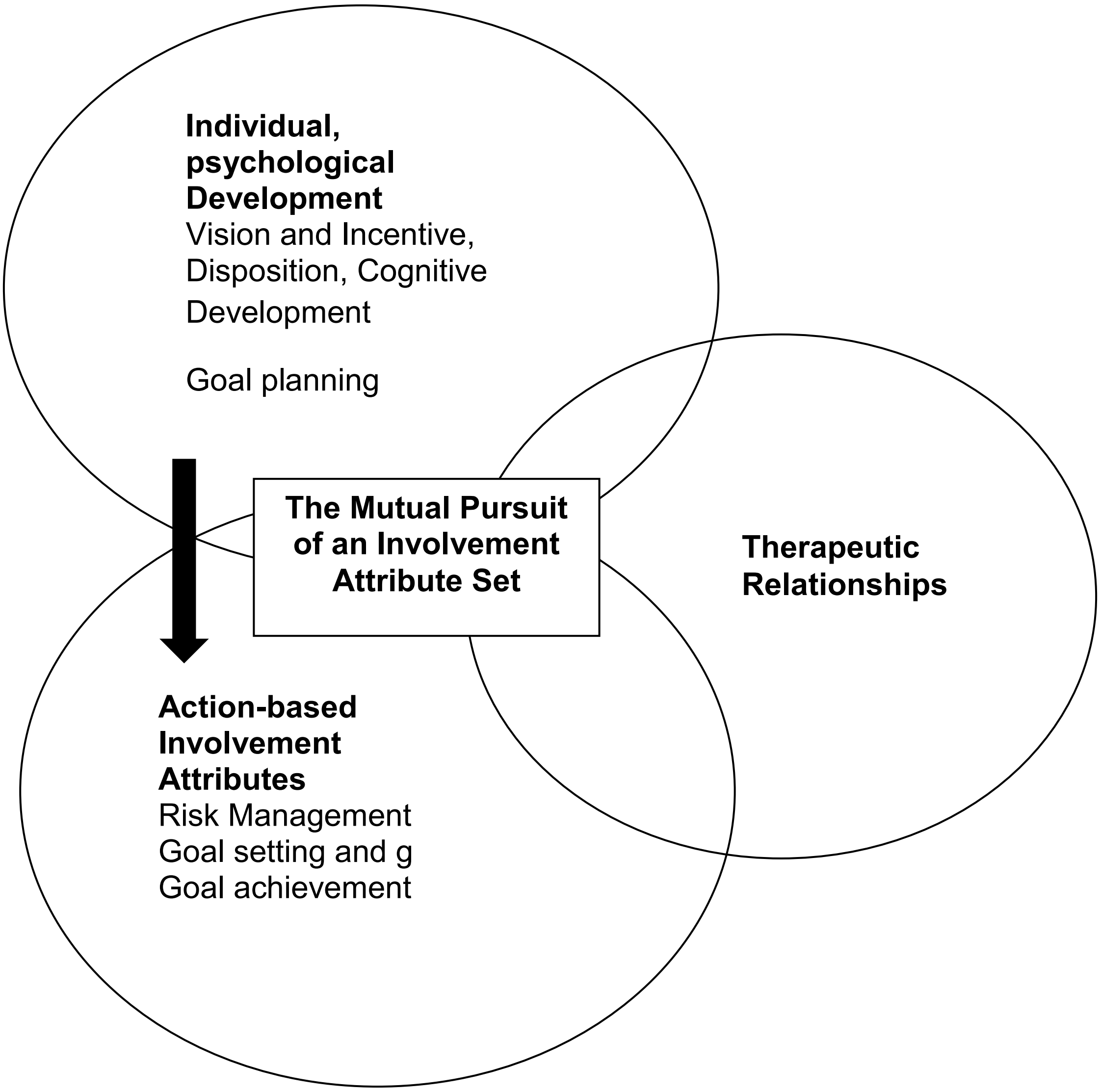
2. Action-Based Involvement Attributes, (Risk Management and Goal, setting and achievement).

   Goals link the two groups and the action-based Involvement group are products of the psychologically-based Involvement group (first presented as Figure 5.1 and redrawn here as Figure 10.1for convenience).

3. The Involvement Attribute set (both groups) operates within the therapeutic relationship which constitutes the third conceptual province (Figure 10.1).

The involvement Attribute set is moulded together in relationships, through a mutual pursuit of a fusion of horizons at some level (Figure 5.1 and redrawn here for convenience Figure 10.1). This will be discussed fully in the relationships section of chapter eleven (Study Discussion). For now, therapeutic relationships provide an opportunity to strengthen involvement through a mutual pursuit of the Involvement Attribute Set.

Figure 10.1 The Involvement Attributes and their Interrelationships



Involvement is maximised when the Involvement Attributes are strong, balanced and there is alignment between the psychologically-based and the action-based groups. Strong means that the Involvement Attributes operate well, balanced means that the Involvement Attributes operate at the same strength and aligned means that the action-based Involvement Attributes flow from the psychologically-based Involvement Attributes.

This constructed substantive Theory of Involvement explains the involvement of all four participants. The different Involvement Attribute sets of the participants within the fairly stable therapeutic relationships the participants had with the staff, worked for or against the participants in the development of involvement in their rehabilitation.

Explanation of the Theory of Involvement Using the Research Constructions

Jack developed the strongest involvement of all the participants. Jack had a strong Vision, concerned with the restoration of his abilities, full range, four types of Goals, positive Disposition, towards rehabilitation and was able to Develop Cognitively. Jack also developed a personally owned Risk Management strategy. It is possible that Jack did have some imbalance in his goals between what he thought he could do and his actual abilities. This imbalance was associated with a high risk of falling and therefore demonstrates slight misalignment between the psychological Involvement Attribute and the action based Involvement Attribute groups.

Jack’s level of involvement was managed within relationships that were largely paternalistic initially but this included some more collaborative interactions as Jack worked increasingly on his own pathway over time (Table 10.8).

Table 10.8 Jack's Involvement Attributes

	Goal (Planning)	**Cognitive Development**	**Disposition**	**Vision and Incentive**	**Slight misalignment**
	Strong	Strong	Strong	Strong	
Goal Setting and Achievement	Strong possibly too strong	Balanced	Balanced	Slightly Imbalanced	
Risk Management	Strong	Balanced	Balanced	Slightly Imbalanced	

Gordon's initial weak Vision and Incentive did not develop during his rehabilitation stay and from this Gordon developed only weak psychologically-based and action-based goals. Importantly pre-functional goals were completely absent which unbalanced the Goal set. Additionally, Gordon did not cognitively learn much about his impairments and how these might be reduced preferring to let others direct him which weakened the psychologically-based Involvement group. Within Disposition, Gordon's weak Vision and Incentive spawned little hope and Gordon did not demonstrate enthusiasm for his rehabilitation. Overall Gordon's Disposition matched the strength of his Vision and Incentive and Cognitive Development but there was imbalance in the goals which only served to weaken involvement further (Table 10.9). This involvement state meant that Gordon's weak psychologically-based Involvement Attributes were aligned with his weak action-based Involvement Attributes, apart from the imbalance in the goals, which did not cause a serious disjuncture between them.

Gordon did not really mind where he was cared for and allowed others to manage the risks within his daily activities. His level of personal Risk

Management was therefore weak and his action-based goals remained vague after discharge. Gordon's overall weak involvement facilitated paternalistic management by the staff of the Intermediate Care unit and his carers at home (Table 10.9).

Table 10.9 Gordon's Involvement Attributes

Involvement Attributes	**Goal (Planning)** Weak	**Cognitive Development** Weak	**Disposition** Weak	**Vision and Incentive** Weak	**Mostly Aligned**
Goal Setting and Achievement	Weak no pre-functional goals	Balanced	Balanced	Balanced	
Risk Management Involvement	Weak	Balanced	Balanced	Balanced	

Joe had a strong Vision and Incentive. Joe's main goal associated with this was to go home. This was a social participation goal which subordinated some of the action-based goals (primarily pre-functional) and facilitated Joe concentrating on rehabilitation outcomes instead of the processes of rehabilitation. The concentration on the social participation goal unbalanced his Goal set. Joe did not learn about himself and his impairments in ways that he could use for himself, for example, he did not begin to understand the relationship between exercise and ability. This weakness was significant and moderately misaligned the psychologically-based Involvement Attribute group with the action-based Involvement Attribute group. Associated with this weak Cognitive Development was a dependency on the physiotherapists which facilitated paternalistic relationships with the staff and led to a lack of ownership of the rehabilitation process and particularly a weak Risk Management Involvement Attribute. Within this system Joe had a strong Disposition towards rehabilitation, was enthusiastic about his physiotherapy and hopeful especially early in rehabilitation. When the direction of the physiotherapists was removed after discharge from the Intermediate care unit Joe was left perplexed.

Overall Joe's Involvement Attributes were moderately unbalanced and moderately misaligned. This imbalance occurred firstly between the goal types and secondly between Joe's Vision and Incentive, Disposition and Risk Management. The strong psychologically-based goal, of wanting to go home contrasted with the absence of pre-functional goals and weak personally owned Risk Management strategy causing the misalignment (Table 10.10).

Table 10.10 Joe's Involvement Attributes

Involvement Attributes	**Goal (Planning)** Social participation strong	**Cognitive Development** Weak	**Disposition** Strong	**Vision and Incentive** Strong	**Moderate Misalignment**
Goal Setting and Achievement	Imbalanced Absent pre-functional strong social participation	Imbalanced	Imbalanced	Imbalanced	
Risk Management	Weak	Balanced	Imbalanced	Imbalanced	

Josie differed from the other participants in that during her long stay in the Intermediate Care unit she became bedfast and physically reliant on the staff. During this time, Josie's psychologically-based Involvement Attributes developed strongly. Unlike the other three participants whose rehabilitation Vision and Incentive was concerned only with going home, Josie's Vision and Incentive had two parts. The first part was concerned with where she was going to live and the second with what she would do when she got there. Additionally, Josie did not have a consistent mood which left her socially needy on some days and buoyant on other days when she was socially very competent.

Notwithstanding Josie's inconsistent moods, overall she had a strong and positive Disposition. Josie's motivation and her enthusiasm, assisted by Cognitive Development, were used to make the decision and to work towards moving into a Nursing Home. This included the choice of Home and the room furnishings.

In the second part of Josie's vision, Josie set some social participation goals that required physical ability, (requiring pre-functional, functional and activity goals) that she could not attain. For example, Josie saw herself walking to the toilet and riding on a motorised scooter to social events in the Nursing Home. Since Josie was bedfast neither of these were possible. This caused a serious imbalance in her goal set and a serious misalignment between Josie's Cognitive Development and physical Risk Management strategies. On the one hand Josie wanted to manage physical risks by herself but in reality Josie's physical risks were managed by others. This serious misalignment represents a disjuncture between the two groups of Involvement Attributes and may have had some association with Josie's despair after discharge from the Intermediate Care unit. Overall Josie's

Involvement Attributes were strong with some imbalance and were severely misaligned.

Josie developed a variety of relationship types in the Intermediate Care unit. In physical care these were a mixture of paternalistic to partnership relationships. Socially, Josie developed some collaborative partnership relationships which she thought of as friendships. These facilitated Josie's complex organisation of her life in the Intermediate Care unit (Table 10.11).

Table 10.11 Josie's Involvement Attributes

Involvement Attribute groups	**Goal (Planning)**	**Cognitive Development**	**Disposition**	**Vision and Incentive**	**Severe Misalignment**
	Strong	Social Strong Physical weak	Strong	Strong	
Goal Setting and Achievement	Strong functional and activity-based goals. Absent pre-functional goals	Imbalanced but in the Nursing Home more balanced	Imbalanced	Imbalanced	
Physical Risk Management	Very weak	Very Imbalanced	Very imbalanced	Imbalanced	
Social Risk Management	Strong	Balanced	Balanced	Balanced	

Part Three

Chapter Eleven: Study Discussion

Introduction

The constructions in the previous chapter concluded that the meaning of involvement for older people in rehabilitation after acute illness is manifested through an Involvement Attribute set managed within the relationships developed during rehabilitation. The use of these Involvement Attributes explains the Theory of Involvement.

Using the constructions, the meaning of involvement for older people in their rehabilitation after acute illness is

> “A joint commitment within therapeutic relationships to determine and be determined in the pursuit of an Involvement Attribute set that is strong, balanced and aligned”.

This research has developed a system of ideas which explains involvement in rehabilitation through the association of the Involvement Attributes within relationships between older people and health care staff. This level of explanation defines a theory (Hawker and White, 2007, Walker and Avant, 1988). Although explanation for its own sake is worthwhile, a deeper understanding of involvement, in the terms of these research constructions, may assist health care practitioners and their support workers, to promote and predict involvement in their relationships. These improved health care processes will enhance the impact of the policy-driven structures discussed in chapter two (Background).

This chapter discusses the analysis of the current research, explaining the argument for the Theory of Involvement through the association of the constructions in this current research with relevant health care practice-based research literature. The individual, psychologically-based Involvement Attributes are discussed first followed by the products of these, the action-based Involvement Attributes. However, the Involvement Attributes do not manifest themselves in rehabilitation except through relationships. Hence, relationships are considered throughout the discussion and will be discussed more fully in the relationships section of this chapter.

Next, the argument is located within a wider social context and theoretical framework, associating the meaning of involvement with the Triadic Reciprocal Causation model (Bandura,1986). Person-centred care is then discussed as a framework for care that incorporates the Theory of Involvement.

The interdependency of the Involvement Attributes discussed in the construction chapters, is no less important in this more conceptually managed chapter. However, once again, for ease of study, the Involvement Attributes have been segregated into their conceptual provinces as discussed at the end of the constructions chapters, (chapters five to ten).

Psychologically-Based Involvement Attributes

Involvement requires Cognitive Development, a Disposition concerned with hope, motivation and enthusiasm and Incentives directed at the achievement of a Vision. These individual issues have not been described directly in this context in the literature, but their importance has been recognised. In their qualitative study about physical and occupational therapist perceptions of patient engagement (a term sometimes used synonymously with involvement in rehabilitation) Lequerica, Donnell et al (2009) reported that almost all the occupational therapists in their sample, regularly documented information about patient engagement. However, the constructs of involvement, used by the therapists, were individually defined making it difficult for them to use the concepts collegially. Efforts to capture involvement are therefore prone to value judgements (Siegert and Taylor, 2004). This is not surprising, as it is easier to describe more transparent, action-based aspects of Involvement rehabilitation, such as goal setting, goal achievement and risk management plans than the more esoteric, psychologically-based aspects of Involvement.

Personal Visions and Incentives

In this current research, Involvement in rehabilitation begins with a personal vision of what life would be like after rehabilitation. This vision initiates a commitment, at some level, to the rehabilitation process. These visions may be activity-based, for example, "I see myself walking" or socially-based, for example "I want to be able to do my own shopping." Where there is no personal vision, or where the personal vision is not expressed, clearly and consistently, the vision is not strong and the person is likely to have weaker involvement. The expression of a strong vision alone is not enough to demonstrate involvement. Associated with the vision, and which strengthens it, is an incentive to achieve that vision. Positively-worded statements such as “I want to be with my family” and negatively-worded statements such as “I don’t want to have to go into a Nursing Home” are useful ideas that demonstrate the possibility of stronger involvement in rehabilitation than, for example, the expression of a desire to be at home with no particular reason for the achievement of the vision. A lack of personal incentives, or where the personal incentive is unclear, inconsistent or not personally owned, demonstrates a potential weakening of involvement.

In the constructions of this research, some older people had strong personal visions at the start of rehabilitation that were developed throughout their rehabilitation, whilst others developed a vision during their rehabilitation stay, adjusting their personal visions as they progressed. In both cases the visions were adjusted through interaction, largely with staff, through cognitive learning. Practitioners may be able to use this information about visions to facilitate ownership and assess the type and strength of vision, incentive and goals the patients possess, as they work with their patients.

There seems to be a dearth of research about the use of the formation of a Vision and Incentive in rehabilitation. Kurz et al.(2008) recognised the role of the patient when they used the visions of recovery of three people, in the form of an imagined recovery path to discern their recovery preferences during rehabilitation. Kurtz et al. (2008) suggested that discussions, which include recovery path exploration (RPE), are useful for increasing the depth of discussions about how people with disabilities see their recovery trajectory.

In the light of this current research these discussions could be used to assess and predict involvement.

In other work, the development of a Vision is condensed into goal setting, discussed later in this chapter. Wade (1999), in a commentary paper, discussed a range of concepts concerned with goal setting in stroke rehabilitation. Wade (1999) used aims, equating to Visions, objectives equating to Goals and introduced targets as immediate goals. However, even if the above terms are seen as comparable, Wade (1999) misses the importance of the role of the patient and their psychological development in the formation of goals. Additionally, he does not emphasise the role of relationships, so important in psychological development in rehabilitation. In practice, an understanding of the role of the patient, particularly their psychologically- based Involvement Attributes will provide the opportunity to facilitate involvement.

Cognitive Development

Within the definition of involvement, the term Cognitive Development was used to represent a process of personal learning demonstrated within the rehabilitation. This learning embraced adjustment and adaption. There are many types of learning, those discussed here are those directly concerned with the constructions in this current research. Operant learning (Wood and Alderman, 2011) in rehabilitation is concerned with activities, usually prescribed by the health care professionals. Learning about the process and outcomes of these activities provides information to the therapist, who is able to prescribe other activities (Fordyce, 1976). In this current research and from the participants' perspective, learning is operant when there is a simple relationship between the level of success of an activity and the prescription of future rehabilitation work. Operant learning took place in many of the paternalistic therapeutic situations observed during the data collection-analysis period.

Cognitive Development, Cognitive Learning and Involvement

In this current research, the term Cognitive Development was used to describe how an adult may use the period of rehabilitation as an opportunity to learn and adapt that learning, with versatility to suit themselves. Cognitive Development is separated from operant learning and action based in instruction from others. Examples of Cognitive Development can be demonstrated by actions such as, organising assistance to achieve personal goals. As the person begins to adjust and therefore determines the environment, through learning and action, he demonstrates involvement. Although operant learning is necessary in rehabilitation it is cognitive learning that is important in involvement.

There is a paucity of research that directly relates involvement and cognitive learning. However, in a multiple baseline single-subject design (where the participants acted as their own control) using six participants with back pain, Linton et al (1999) reported that where goal sharing occurs, outcomes are improved. Goal sharing, between staff and patients, is suggestive of cognitive learning as the goals are formulated between the staff and the patient. Ostlund et al.(2001) support this finding in their grounded theory study of 20 people who had been absent from work due to muskulo-sketetal problems. This study suggests that cognitive learning, through the use of individual rehabilitation measures and goals is important in rehabilitation.

In this current research, those participants who were able to develop cognitively in a balanced way and aligned to the other Involvement Attributes, demonstrated Involvement in three ways: firstly, when cognitive learning was evident as the participant moved from functional dependence towards independence. This was exemplified as the participants began to understand their personal limitations in relation to the work to be done. Secondly, when cognitive learning took place within the participant's personal care and self-management, for example, as they used their increasing strength to manage their own care. Lastly, involvement was demonstrated when opportunities were taken for cognitive learning related to changes in family and home circumstances, for example, the move from home to a Nursing Home, the requirement for home alterations and the changing relationship with partners.

Cognitive learning in rehabilitation was only made transparent through action. With stronger involvement this action may be referenced to independent thinking, for example, asking the family to bring in those items that might bring more comfort such as "Posh Inco pads" used so that the number of bed changes per day could be reduced. Other examples occurred when cognitive learning was used to aid functional progress for example, organising extra food used to build up stamina. Without cognitive learning and the concomitant actions, involvement was weakened and actions were either left undone, or managed by an external source. Participants in this study who, in spite of functional improvement, did not learn about themselves in a cognitive way, demonstrated through action, were less involved in their rehabilitation than those who did learn in a cognitive way and could translate this into action. This demonstrates the requirement for alignment and balance in the management of the Involvement Attributes.

This individualistic approach to cognitive learning, concerned with the relationship between individual cognitive learning and action, is in keeping with Mezirow's (1991) view of adult cognitive and transformational learning. However, individualistic approaches to learning in rehabilitation, underplay the relationship between the person in rehabilitation and the staff of the Intermediate Care unit. These relationships were important in this current research, because the majority of new information about rehabilitation was provided by the practitioners and their support workers. In this respect, the power in the relationship with the participants, initially at least, resided with the staff.

Pertinent to the nature of relationships in rehabilitation, but on a much grander scale, is the work of Freire (1970) which suggests that where the power levels within community life are unequal, cognitive learning is more difficult. This provides an insight into the difficulty the "have-nots" (Tritter 2003) might move up Arnstein's (1969) Ladder of Citizen Participation discussed in chapter two (Background). Although power relationships were not considered in this current research, it is acknowledged that these are important and further study should consider these.

Disposition

The individual disposition of the person in rehabilitation is an important part of involvement and comprises the emotions and emotional effort associated with the processes and accomplishments of rehabilitation. The elements of disposition that are important in the Involvement Attributes are *Hope, Motivation and Enthusiasm.* These components of disposition are viewed by some to be solely based in the individual. For example, Elster (1989) reported that the unit of social life is individual action and that social institutions are made up of the interactions of individuals. However, from a symbolic interactionist perspective, the social institution, in this case the work in the Intermediate Care unit, also determines the individual through the

> "Convergence and divergence of values in the therapeutic encounter, the qualities of the rehabilitation staff and the nature of the patient's social support networks" (Maclean and Pound, 2000).

From health care practice research, Hesse and Campion (1983) reported that when the reasons for rehabilitation exercises were not made clear to older people, they were less motivated to perform the activity. However, in the Hess and Campion (1983) research, it was not discussed how the exercises were made clear. For example, if clarity was based on a description of the exercises or demonstration of the exercises, mastery might be based on operant learning with the power in the relationship remaining with the staff. If clarity was based on assisting the person in rehabilitation to find out about the exercises, then this is more likely to include cognitive learning and personally-owned motivation and enthusiasm which will strengthen the Involvement Attributes.

Hope

There were four types of hope described in chapter seven (Disposition, Table 7.1). These were useful hope, no particular hope, unreasonable hope and blind hope. Useful hope is related to stronger involvement, and in this current research, was demonstrated most predictably, through the achievement of incremental goals, working towards a Vision that was personally owned and achievable. Useful hope was also demonstrated when situations demanded a step change or transformation in perspective (Mezirow, 1996) as opposed to incremental change, for example, the move into a Nursing Home rather than returning home. In this case, there was hope that a pleasant environment in the Nursing Home would be made available.

Hope is most useful when it is aligned with other psychologically-based Involvement Attributes and is sustainable through the personal efforts of the individual and those with whom the individual is interdependent, for example, the staff of the Intermediate Care unit. The system is informed within the relationships developed during rehabilitation.

Functional progress in rehabilitation and hope are not inextricably linked. Functional progress, led by staff, can take place even when older people demonstrate no particular hope. It is difficult to demonstrate the presence or absence of hope except thorough expressions of the action-based Involvement Attributes such as goal-orientated language and positive gestures concerned with the desire to achieve goals. Expressions such as “I want a quiet life” and related inaction, convey less hope than “I need to build up my stamina”, related to personal intervention to eat more food, to attain strength to improve functionally. The former requires little or no action and the latter predicates the intention of affirmative, personally-driven, action and indicates a stronger involvement.

The absence of clear vision-based, goal-orientated, expressions of hope weakens the psychologically-based Involvement Attributes and effects weaker Involvement. Without a Vision and Incentive and Cognitive Development related to clear Goals as part of the rehabilitation process, Hope does not flourish. Where the psychologically-based Involvement Attributes are all weakened there is a reliance on external sources and an absence of a personally-owned Risk Management Strategy. Progression in rehabilitation in this system is sustainable mainly through the efforts of others rather than the personal efforts of the individual and requires facilitative relationships.

There is evidence that useful hope can flourish where the Vision and Incentive and personally set goals are unattainable (chapter six, Vision, Incentive and Goals, Table 6.2). In agreement with this, Snyder (1999), points out that hope is an internalised belief about achievement, a *perceived* capacity to produce achievement components. These components (goals, pathways and agency (Snyder et al., 2005) may be unrealisable. In this current research, this was called unreasonable hope and was demonstrated in one participant who had a misalignment between the psychologically-based Involvement Attributes and the action-based Involvement Attributes, (discussed in chapter ten, Relationships, in the conclusion to the constructions). This type of hope may have a protective feature. The possession of hope may have provided reasons for one participant to be pleased about her circumstances, associated with limited control of realistic choices.

Unreasonable hope provides strength to the other psychologically-based Involvement Attributes but this may not be sustainable in the long term. Progression in this system is sustainable, as long as the Vision and Incentive and goals remain unchallenged by the individual, either through their own agency or the efforts of others. Once this challenge occurs, the misalignment becomes transparent which weakens the psychologically based Involvement Attributes. When unreasonable hope occurs, therapeutic relationships become important as a vehicle of involvement management. In this current research, there was an absence of a mutual pursuit of a fusion of horizons between one participant and the staff with respect to unreasonable hope.

The last type of hope is blind hope which is associated with *a* Vision and Incentive based on rehabilitation outcomes, for example, social participation goals, as opposed to a Vision and Incentive based on personal performance and accomplishment (pre-functional, functional and activity-based goals. Blind hope features another imbalance of the psychologically-based Involvement Attributes and so weakens involvement. In this current research the strength of the blind hope was matched by the absence of Cognitive Development and the Reliance and Trust the participant had in the staff. This is consistent with strong motivation to work under the direction of those trusted to achieve their goals. This system is managed at the expense of the development of endogenous trust, Cognitive Development and a personal Risk Management strategy. Progression in this system is sustainable as long as others are providing the direction, for example, managing the rehabilitation in the Intermediate Care unit. Once this direction weakens, example, on discharge, the Blind Hope diminishes and a new alignment of the *psychologically*-based Involvement Attributes will need to be set up. The therapeutic relationship is important in the presence of Blind Hope because this is a symptom of an unbalanced group of psychologically-based Involvement Attributes. Staff should work to facilitate a change in horizons in the patient to rebalance the group.

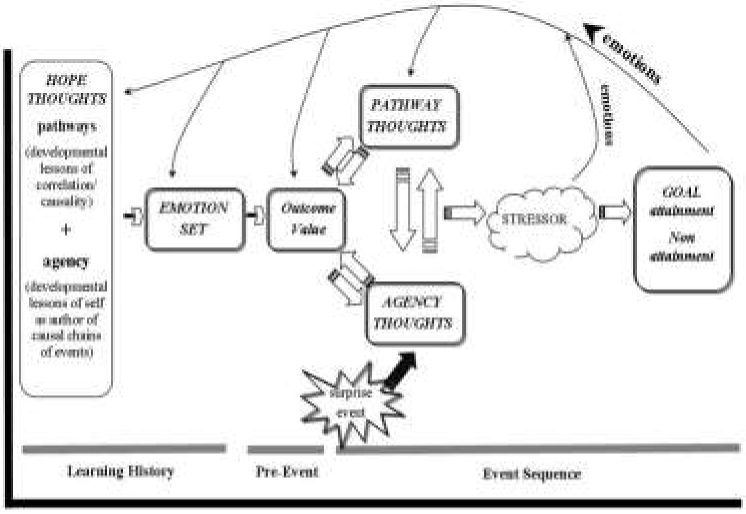
The four types of hope described here and summarised in Table 11.1 are probably not exhaustive. However, the examples clearly show the relationship between hope and the other psychologically-based group of Involvement Attributes. This relationship can be used by practitioners in both assessment and intervention activities within rehabilitation.

Table 11.1 The Relationships between the Different Types of Hope and the Two Groups of Involvement Attributes

Type of Hope	Relationship to the Psychologically-based and Action-Based Involvement Attributes in terms of strength balance and alignment	Fusion of Horizons with rehabilitation goals	Sustainability	Involvement
Useful Hope **Jack**	Strong Balanced Aligned	Strong	Personal effort within relationships	Strong
No Particular Hope **Gordon**	Weak Balanced Aligned	Weak	Acceptance of external resources who provide direction	Weak
Unreasonable Hope **Josie**	Strong Balanced Misaligned	Weak	Personal effort within relationships with No serious cognitive challenges to the hopes	Strong, but the misalignment weakens hope long term
Blind Hope **Joe**	Strong Unbalanced Aligned	Apparently High	Trust in external resources who provide direction	Apparently Strong but may be weakened when direction is removed

A hope pathway in rehabilitation has been discussed (Snyder et al., 2005) (Figure 11.1 below). Figure 11.1 summarises how a person may respond to an event, expressed as a stressor. This is related to hope thoughts, pathways and agency, emotion sets, outcome values, stressors and goal attainment or non-attainment. Hope thoughts, relating to the attainment, or non-attainment, of goals depend on emotion sets and the perceived outcome value of the goal. These assist in the production of pathways to achieve goals through the use of a level of personal agency. Pathways to success or failure require agency and self-belief, which are used and learned over time, and become embedded into the persona as developmental lessons. As stressors potentially prevent the attainment of goals, hope thoughts affect goal attainment.

Figure 11.1 Hope in Rehabilitation (Snyder 2005)



(Reproduced by kind permission of APA publications in Snyder, C., Lehman, K., Kluck, B. & Monsson, Y. 2005. Hope for Rehabilitation and Vice Versa. *Rehabilitation Psychology,* 51**,** 89-112.

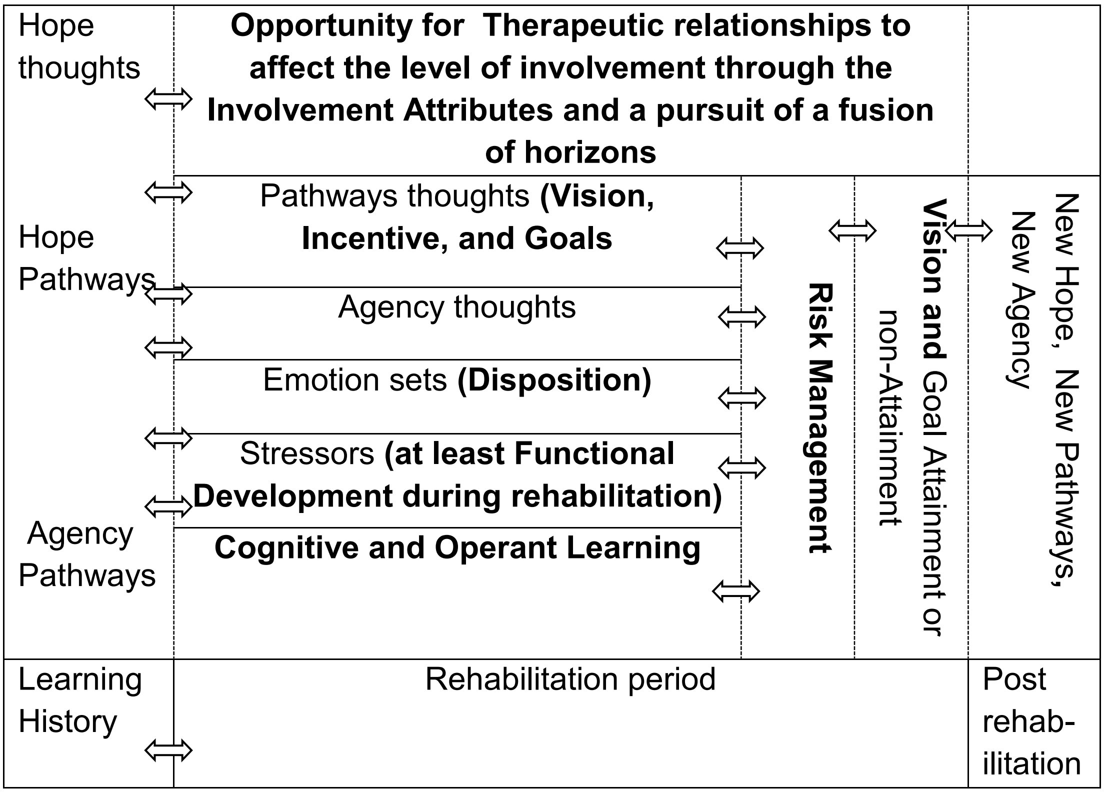
The constructions of this current research confirm and expand the work of Snyder (1994) and Snyder et al (2005) who suggest that those who have high hopes are more likely to attain the personal goals set for themselves in rehabilitation. This is because people with high hopes perceive ways forward, based on past experiences.

Associations between this current research and hope theory include the relationship between hope and the rest of the Involvement Attributes. Those participants with strong, balanced and aligned Involvement Attributes including high hopes, had more clearly specified goals than those with weaker involvement who had more vague goals (Snyder et al., 2005). However, goals are only part of the Involvement Attribute set. Where the Involvement Attributes as a whole were weaker, unbalanced and/or misaligned different types of hope, for example, no hope, blind hope and unreasonable hope, were produced, (Table 11.1).

Particularly relevant to the work led by Snyder (Snyder et al., 2005), is the notion that high hope results from individualistic, dispositional forces or external treatment forces led by the staff. In this current research, where hope was increased by dialogue with the staff without the support of the other Involvement Attributes, the apparent level of involvement was increased. Where the dialogue included the joint pursuit of a fusion of horizons with regard to rehabilitation outcomes, involvement was more real than apparent (Table 11.1).

In Figure 11.2, below, the differences between the hope theory, Figure 11.1 (Snyder et al 2005) and this current research are presented. The differences are concerned with the inclusion of the Involvement Attributes and dialogue in relationships. Moving from left to right in Figure 11.2, hope thoughts, hope pathways and agency pathways (the participants learning histories developed prior to rehabilitation, are developed during the rehabilitation through therapeutic relationships leading to pathway thoughts, agency thoughts emotion sets, stressors and learning. These lead to different types of risk management strategies, new vision and goal attainment and, post discharge, to new hope, new pathways and new agency. Importantly, cognitive and operant learning, which take place in rehabilitation, have an affect on Risk Management strategies. This knowledge that can be used by health care staff within a therapeutic relationship, to manage the Involvement Attribute set through the pursuit of a person-centred care framework with people in rehabilitation.

Figure 11.2 Showing the Similarities and Differences between the Theory of Involvement and Hope theory (Snyder 2005) within a Rehabilitation Period



Bold Font = Involvement theory constructions. Black Font= Hope theory (Snyder 2005).

Motivation and Enthusiasm

Motivation and enthusiasm are closely linked concepts and are sometimes thought to be interchangeable (Hawker and White, 2007). However, these terms are distinguishable in that motivation, one reason for action, is the drive to achieve a goal and enthusiasm gives direction to the motivation drive in terms of keenness and eagerness in a particular domain. Emmons (1996) suggests that patients' emotions and feelings, for example, motivation and enthusiasm, are expressed in the goal-setting process. In this current research, motivation and enthusiasm were associated with involvement through the action- based Involvement Attributes such as goal setting and achievement and the Risk Management strategy. The Involvement Attributes were strengthened where motivation and the directed enthusiasm resided within the individual (endogenous). The Involvement Attributes were weakened where the motivation and directed enthusiasm were external (exogenous), for example, residing with the staff.

Motivation

Motivation is an individual, psychological drive which is positively associated with rehabilitation outcomes (Maclean and Pound, 2000). Motivation may be exogenous, for example, provided paternalistically by the staff of the Intermediate Care unit, with little reference to the personal goals of the person in rehabilitation. Motivation may also be endogenous, emanating from within the person in rehabilitation. Where motivation is present, knowing the source, and how motivation is directed (enthusiasm), is useful as part of understanding the Involvement Attributes as a whole and therefore Involvement in rehabilitation.

In this current research, where motivation was present and exogenous then, predictably, this was most often directed towards caring or rehabilitation functions. These included, caring when the participants were too weak to help themselves and the provision of rehabilitation at the levels of body part, activity and social participation. Where motivation was present and endogenous, this was directed in two different ways. Firstly, the motivation was directed at the rehabilitation work, which operated in much the same way as the practitioners operated, and tended to be at the level of body part, or activity. Secondly, motivation was directed to organise others and to make life comfortable. Table 11.2 summarises how different types of endogenous and exogenous sources of motivation and enthusiasm are associated with the Involvement Attributes and the locus of control.

Table 11.2 Summarising how Different Types of Endogenous and Exogenous Sources of Motivation and Enthusiasm are Associated with Levels of Involvement and the Locus of Control

	1	**2**	**3**	**4**
Source of Motivation	**Endogenous**	**Exogenous**	**Endogenous**	**Exogenous**
Source of Enthusiasm	**Endogenous (Directed personally)**	**Endogenous**	**Endogenous (Directed socially)**	**Exogenous**
Aims of Personal Enthusiasm	To improve body functioning	To maintain or build relationships by accepting the authority of the source	To maintain relationships for personally directed social reasons	No personal enthusiasm but reacts to the enthusiasm of others
Examples	Self-directed exercising	Eagerly participating by request	Caution in language and gesture with authority	Persuaded into rehabilitation tasks
Involvement Attributes	Strong Balanced Aligned	Weaker Imbalanced Aligned	Strong Balanced Aligned	Weak Balanced Aligned
Level of Involvement	Strong	Superficially Strong and remains until the external motivation is removed	Strong	Strong
Locus of control	Towards Participants	Towards staff	Towards Participants	Towards Staff

Enthusiasm

This section is summarised in Table 11.2, above. Involvement in rehabilitation was demonstrated most when motivation is endogenous and the harnessed enthusiasm is directed at some aspect of rehabilitation such as physical or social functioning (Table 11.2). There were four main ways that enthusiasm was harnessed in this current research, each had different effects on the Involvement Attributes and each strengthened or weakened involvement.

The first way enthusiasm was harnessed was related to pre-functional activity, for example, building strength. This type of enthusiasm strengthens the Involvement Attributes and helps to increase the level of involvement because the enthusiasm is aimed at direct, personal achievement through the process of rehabilitation. Secondly, there was enthusiasm for pleasing the staff within the therapeutic relationship. This either helped to confirm the presence of exogenous motivation or was recognition of the authority of the practitioners, concerned with the power the participant perceived the practitioners possessed, for example, over discharge dates. In the former, pleasing staff demonstrated weakened Involvement Attributes which effected reduced involvement associated with a reduced interest in the *process* of rehabilitation and an acceptance that the control was with the staff. In the latter, pleasing staff demonstrated caution; enthusiasm was associated with a facilitation of personal achievement, the desired goal of discharge from rehabilitation and so strengthened the Involvement Attributes and increased the level of involvement.

A third type of enthusiasm was directed socially. This was done within relationships with the staff to facilitate co-operation and an acceptance of being organised by the person. Using the arguments above, this type of enthusiasm strengthens the Involvement Attributes and increases the level of involvement. Lastly, a lack of enthusiasm is demonstrated through a lack of endogenous motivation which therefore cannot be harnessed. Where this occurs, external, exogenous motivation and enthusiasm has to be maintained to achieve progress. In this situation the strength of the Involvement Attributes is weakened and involvement is reduced. This lack of enthusiasm was demonstrated in this current research, by noting the different types of enthusiasm that others possessed and associating the absence of this, and any other type of enthusiasm, in the participant.

The Locus of Control, Motivation and Involvement

The locus of control is concerned with how much a person believes that a person's actions determine outcomes. Those with a strong internal locus of control believe that they can determine outcomes and those who have an external locus of control believe that outcomes cannot be affected by personal endeavour (Rotter 1966). Individuals can be placed along a continuum of external and internal control.

Where the motivation and enthusiasm are both endogenous, this strengthens the Involvement Attribute set and, assuming strength balance and alignment in the other Involvement Attributes involvement is increased. When involvement increases, the locus of control moves towards the older person and away from external sources of control. Where both motivation and enthusiasm are exogenous, the Involvement Attribute set is weakened, involvement is reduced and the locus of control moves externally, in this case towards the staff (Table 11.2).

Where the source of motivation is exogenous and that of enthusiasm is endogenous, the Involvement Attribute set is weakened and there may be evidence of an overly reliant relationship in which involvement may be seen as apparently strong, but is substantially weakened when the exogenous source of motivation is removed. This type of enthusiasm moves the locus of control towards the staff (Table 11.2).

The relationships described here can be used by practitioners in rehabilitation in conjunction with assessments of the other components of the Involvement Attribute set. The strongest involvement is attained when motivation and enthusiasm are endogenous and directed towards action-based Involvement Attributes, for example, goals, at all of the four levels, (pre-functional, functional, activity-based and social-participation) and based within a personally owned Risk Management strategy. Rehabilitation outcomes may improve if these concepts were part of assessment and treatment regimes.

Action-Based Involvement Attributes

Goals

Goals are associated with both psychologically-based and action-based Involvement Attributes. In rehabilitation goals are the product of individual, psychological issues (Figure 10.2). In this thesis they are discussed as action-based because goals lead to action.

In this current research, the development of goals provided a lens into the individual, psychological rehabilitation and action-based issues of the participants within their relationships with the staff of the Intermediate Care unit. The participants had four levels of goals, discussed throughout this thesis. To reiterate these for completeness, these were: pre-functional, functional, activity-based and social-participation. The type of goal that predominated in the rehabilitation demonstrated the ways the participants thought about their rehabilitation. For example, social-participation goals dominated where the person was fixed on going home without the consideration of the process of rehabilitation. A person who expresses social-participation goals, without other goals based in the *process* of rehabilitation and personally initiated accomplishment, may be too reliant on others to help him to achieve his vision which weakens the Involvement Attribute set.

Involvement is maximised when all the process-based levels are evident. The process-based goals are different from goals at the level of social-participation because they involve personal performance and accomplishment up to the whole body level and demonstrate commitment to the rehabilitation process, rather than just the outcome.

It is difficult to separate the individual contributions of the participants to the formation of their goals in this current research. This is because each of the participants was in a therapeutic relationship with the staff of the Intermediate Care unit whose role was to create opportunities for functional improvement through goal planning and setting (Muller et al., 2011). Goal planning is an integral part of rehabilitation (Duff et al., 2004, Haas, 1993, Struhkamp, 2004, Wade, 1998) and from this current research is transitional between the “Vision and Incentive” and goal achievement. It is the work in rehabilitation towards different goals, together with the psychologically-based Involvement Attributes and Risk management that lead to progress in rehabilitation. The psychologically-based Involvement Attributes affect the action-based Involvement Attributes. There is also some evidence that the converse is also true, for example, the enthusiasm of one of the participants was reduced when his physical capability began to plateau.

In this current research, if there was misalignment between the vision and goals, the goals or vision may need to become aligned before the Involvement Attributes can be strengthened and involvement increases. Similarly, but this time working from action-based to psychologically-based Involvement Attributes, if the goals were not being achieved then this may require a change in vision. Until this is complete there is a misalignment in the Involvement Attribute set and involvement is reduced.

Much of the literature about the effectiveness of goal planning and setting is written from the perspective of the practitioner, which puts the practitioners in the dominant position in the therapeutic relationship with their patients. For example, Arnetz, Almin et al.(2004) employed a randomised controlled trial of 77 patients to study the effects of patient involvement in goal setting. These researchers concluded that active patient involvement may have beneficial effects on both treatment outcomes and patient ratings of the quality of care. In this study, no mention was made of how involvement could be improved or the type of relationships that would facilitate involvement.

Other studies demonstrate that facilitating involvement may not be widespread. In their study, Baker et al (2001) found that although patients and physical therapists thought the involvement of patients in goal setting was important, in most cases, the patients were not encouraged to be involved in their goal setting. Similarly, Palmadottir (2003), discussed in more detail below, found that structured, client-centred assessments of abilities were far less common than informal therapy-led approaches. Additionally, Payton and Nelson (1996), in their descriptive study of 20 patients, were surprised to find that the majority of participants had not been involved in goal setting and did not express a concern about this. Similar research includes that of Nelson and Payton (1991) who described a patient participation system and Tripicchio et al (2009) who recognised the importance of patient involvement in physical therapy treatment and devised methods to help physical therapists to involve patients in goal setting and manage patient concerns. However, none of this research was concerned overtly with the goals the participants had for themselves or specifically associating goals with the patients' perspectives. The research studies only reported participation in the goal setting led by the physical therapist. Using the constructions of this current research, staff-led approaches to goal setting are likely to lead to weaker patient involvement than if the ideas for goal setting came from the patients themselves. In patient-led goal setting the increase in involvement occurs because the Involvement Attributes are transparent and therefore could be designed to be aligned, balanced and where possible strong. This type of goal setting would require a more collaborative and partnership relationship demonstrated through the mutual pursuit of the Involvement Attribute Set.

Some studies have indicated the importance of a more equal relationship between those in rehabilitation and the staff. Wressle et al (2002) reported that goal setting was most useful when managed in a client-centred way as this increased motivation and participation. Additionally, Palmadottir (2003), in her descriptive study of 20 patients, reported that occupational therapy, designed to help patients to build a new future, was more "powerful" (p164) than occupational therapy not so closely associated with the patient's life. Significantly in this study, the participants who had perceived that they were taking a goal directed approach, were most commonly those who had been encouraged to take initiative and responsibility throughout the process. This suggests associations between psychologically-based and action-based Involvement Attributes. In their descriptive study of 49 patients Stenner, Courtenay et al. (2011) concluded that patient requirements should lead the level of information and level of involvement. However, a lack of a deeper understanding of the meaning of involvement would preclude such an undertaking.

Goals at Home

After the rehabilitation period, each of the participants behaved differently towards their continued goal development, which provided further insights into how the Involvement Attributes operated. Those participants who were more involved in their rehabilitation, based on the definition provided by this current research, continued to be involved and those less involved continued in that way.

One participant, who had a strong Vision and Incentive, had been exogenously motivated, led paternalistically during rehabilitation and was left perplexed at discharge (chapter seven (Disposition- Table 7.1 and chapter ten (Relationships -Table 10.4). This participant was possibly making a transition from being directed to directing his future. If his Cognitive Development had been stronger he may have been able to personally own a wider range of goals at all the levels. Through those goals, or an extension of them, he may have been able to progress beyond discharge more easily.

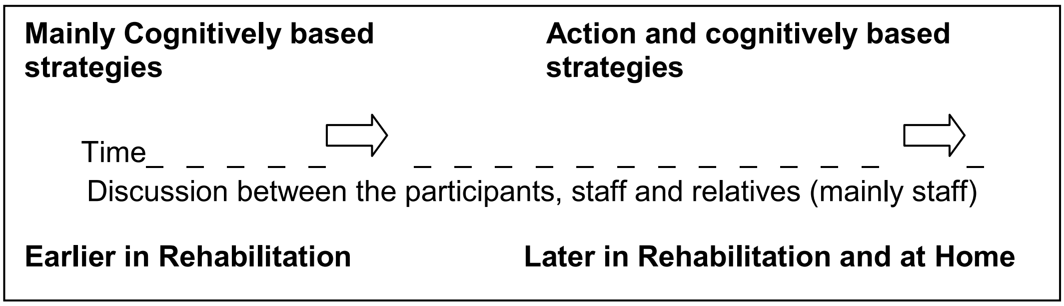
Another participant, whose psychologically-based and action-based goals were misaligned, started to become aware that her goals were not achievable leading to despair (chapter six (Vision, Incentive and Goals, Table 6.2).

Risk Management

The Risk Management strategy, one of the action-based Involvement Attributes, is another product of the psychologically-based Involvement Attributes. Elements within Risk Management include the recognition of personal limitations caused by impairments through self-appraisal, and the associated risk factors. From the constructions in this current research, these are managed through the cognitive processes of decision-making and the management of uncertainty which leads to taking personal responsibility for actions.

In the early stages of rehabilitation, involvement was demonstrated by more cognitively-based risk management strategies, for example, learning about impairments. Towards the end of the rehabilitation, there were more action-based risk management strategies (Figure 11.3). However, reflection and action, mediated by discussion with the staff and relatives, went on all through the rehabilitation period until decisions were made about discharge from the Intermediate Care unit. *Post*-discharge the same types of risk management continued, except that the discussion and any direction, took place through other people, for example, relatives. All four participants demonstrated different types of risk management using this system.

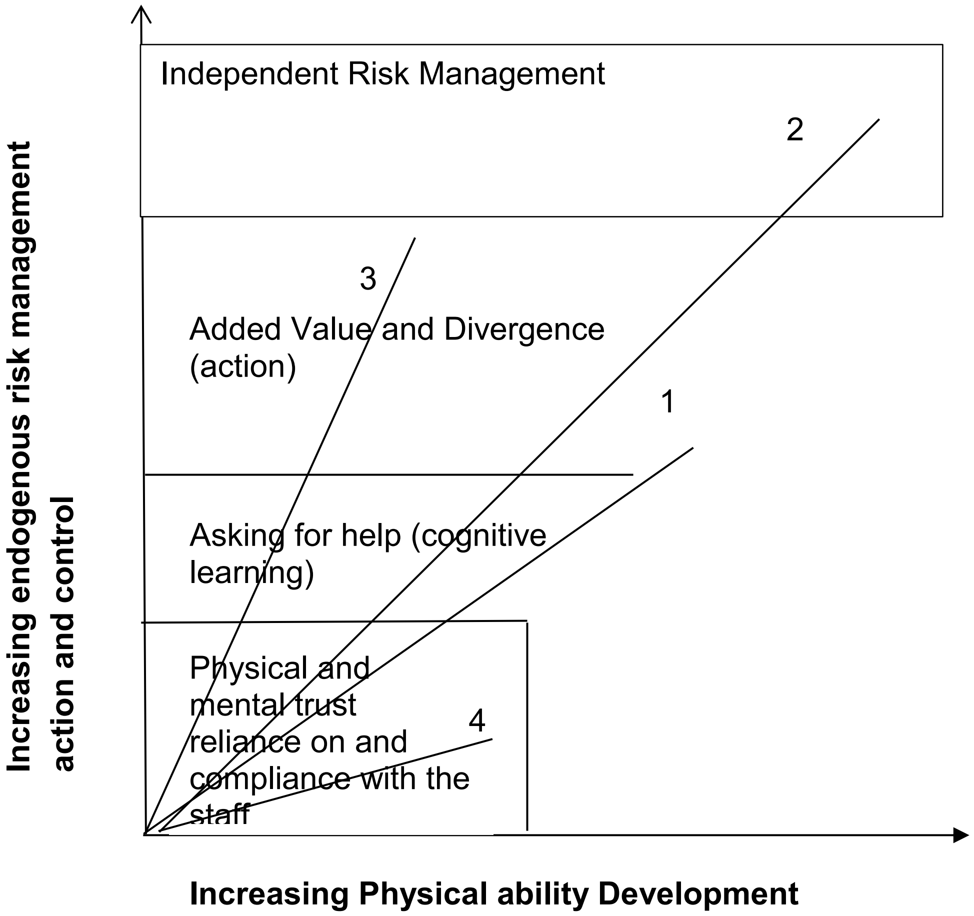
Figure 11.3 Showing the Change in Risk Management Strategy for those with Strong Involvement



One of the main concerns in the Intermediate Care unit was the risk of falling, especially during physiotherapy sessions. Falling was closely managed by the staff at the start of the rehabilitation stay. Risk management is portrayed in Graph 12.1 as the period before Added-Value action, and in Figure 11.3 represented by cognitively-based risk management strategies. Beyond these periods and *post*-discharge, the participants had increasing opportunities to manage their own risk management strategies through asking for help and adding value to the rehabilitation regime.

The participants' risk management strategies were interdependent with the other Involvement Attributes. Graph 11.1, below, shows how an endogenous risk management strategy of increased action and a concomitant increase in personal control (y axis), relates to increasing physical ability (x axis) and involvement. As the endogenous reliance increases with physical ability, involvement increases and the physical and psychological reliance on the external agency reduces. In graph 11.1 the increasing ability is marked as moving through the stages of "Asking for Help" and "Added-Value" (incorporating Divergence) towards "Independent Risk Management" facilitating explorative risk management strategies. Four lines, 1, 2 3 and 4 on Graph 11.1 indicate the range of risk management strategies in this current research.

Graph 11.1 Showing the Expected Relationship between Risk Management and Increasing Physical Ability



Graph 11.1, line one, represents a person who has improved physically to the level of "Adding Value" but has not taken the expected level of endogenous risk management and control. This person has weaker involvement. In the constructions, this was represented by Joe who, early in the rehabilitation, had apparently strong involvement but was acting on the

prescriptions of the staff. If Joe had stronger Cognitive Development, his Involvement Attributes would have been more balanced and he may have been able to move beyond the Added Value stage.

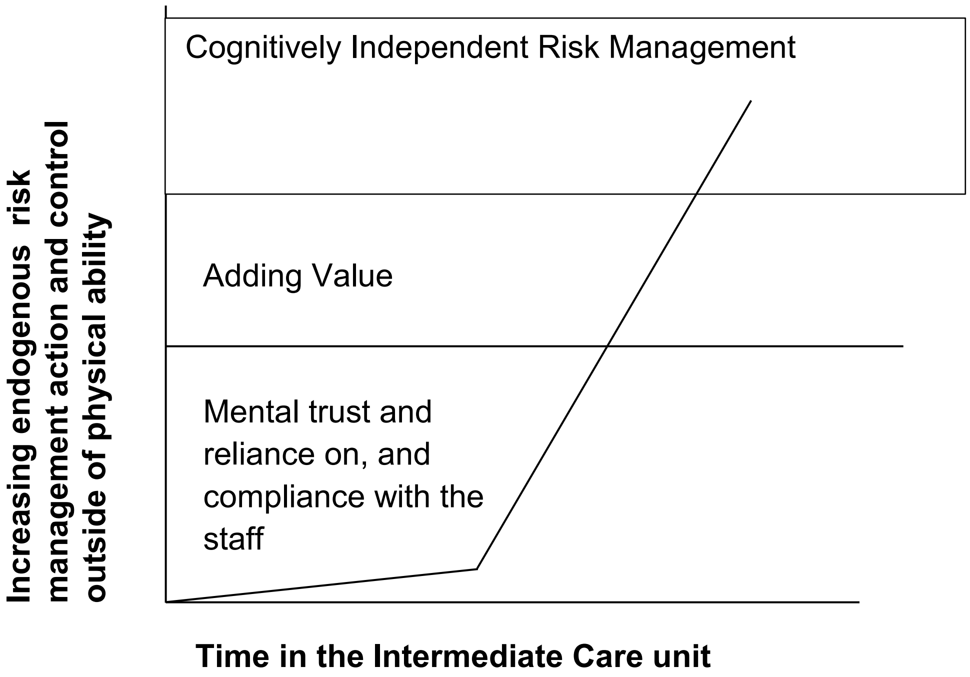
Graph 11.1, line two, represents a person with strong, balanced and aligned Involvement Attributes and the Risk Management strategy taken matched his physical ability as the person moved towards independent risk management. This position is ideal and was not exactly matched in any participant in this current research.

Graph 11.1, line three represents a person whose physical improvement increased but his risk management Involvement Attribute was unbalanced. His will for risk management independence increased faster than his physical ability and he was therefore in danger of falling. This line was matched by Jack in this study, who was likely to fall as the risks taken, were perceived to outstrip his ability by the, perhaps more risk-averse, staff as discussed in Chapter nine (Risk Management).

Gordon is represented by line 4 in Graph 11.1. Gordon's Involvement Attribute set was weak, though aligned and largely balanced which made his involvement in his rehabilitation weak. Although Gordon's physical ability improved slightly his risk management strategy did not move beyond physical and mental reliance. Gordon's Risk Management strategy still needed to be managed by others and his involvement remained weak.

Josie is not represented on the graph because she was bedfast all the way through the data collection-analysis period. This means that there was no physical ability improvement and her control in this area did not increase. However, if the x axis (physical ability) were to be changed to time, the graph for endogenous risk management, action and control, (outside of physical ability), against time, could be drawn for Josie and is demonstrated in Graph 11.2. This facilitates considering her risk management stratagy outside of her physical abilities

Graph 11.2 Showing the way Josie's Progression Related to Endogenous Risk Management, Action and Control of her situation



Graph 11.2 shows the combination of Josie's psychologically-based Involvement Attributes was strong facilitating Josie's ability to take control, make herself comfortable, choose a nursing home and move there. Outside of physical ability Josie's Involvement Attributes were aligned strong and

balanced. However, it was difficult for her to come to terms with her physical ability and she began to despair after discharge from the Intermediate Care unit.

A personal risk management strategy, for those participants whose physical ability is able to be improved, is an important product of rehabilitation as over, or under, performance can lead to, for example, falls and physical deterioration respectively. This was exemplified by Jack and Gordon, respectively in this current research. Therapeutic relationships which facilitate and encourage strength, balance and alignment in the Involvement Attributes provide opportunities to physically improve by matching risk management ability to physical ability.

In their meta-ethnography of qualitative studies related to the risk of falling, McInnes et al. (2011) identified several key concepts concerned with the way older people manage their increased risk of falling. These concepts (self-management, taking control, life change and identity change, salience, rationalizing away and beyond personal control), are relevant to this current research because they demonstrate mind-sets related to the risk of falling and, in this way, are associated with involvement. However, conversely, the McInnes et al (2011) study presents reasons for risk management strategies which is outside the scope of this research.

Risk Management Summary

Overall, two types of risk management emerged in the constructions. The first is rooted within the participant's vision concerned with physical progression. For example, two participants saw progression back to their previous life and identity and worked in different ways towards this (Jack and Joe), while another was accepting of decline and reliance on others (Gordon). The second type of risk management strategy were the actions related to issues outside of physical improvement, such as acting to preserve social participation by choosing to go into a Nursing Home (Josie). With each type of risk management the locus of control was positively associated with the strength of involvement (Graph 11.1).

Where risk management concerns physical function, the strongest Risk Management was demonstrated when the Risk Management Involvement Attribute was aligned and balanced with the other Involvement Attributes. Taking too much risk demonstrates a misalignment between goals (planning) and goals (setting) demonstrating weaker involvement.

Risk management outside of physical functioning provides evidence that the Involvement Attributes may be transferable to other activities. This is discussed under suggestions for further research.

The weakest involvement was demonstrated where risks were not taken and the Involvement Attributes were weaker. In this current research this meant that risk management was left to others, there was poor cognitive development and reflexion, and discussions about progress resulted in action devised by an external source. On these occasions, the locus of control moved towards the staff of the Intermediate Care unit or relatives.

Relationships

Throughout this chapter reference has been made to the role of relationships in involvement. In this current research relationships are concerned with the interdependence of the participants with the staff. This interdependence has been reported to be important in treatment outcomes (Roberts and Bucksey, 2007) and has been referred to as a therapeutic relationship (Besley et al., 2011), or working alliance (Schonberger et al., 2006). The therapeutic relationship has been defined as

> "A trusting connection and rapport established between therapist and client through collaboration, communication therapist empathy and mutual understanding and respect" (Leach, 2005).

This definition identifies the therapeutic relationship as a "connection" and elaborates the relationship qualities of this connection. Another definition of the therapeutic relationship (Gartland, 1984) identifies the relationship as an interaction and, importantly, gives direction to the relationship.

> "A means of communication wherein both therapist and patient interact to achieve a therapeutic goal" p26.

However, both definitions hide complexity within the therapeutic relationship as they necessarily omit the nature of the interactions and the communications. Besley et al (2011) calls for research into a more conceptual measure of the therapeutic relationship and this current research makes some inroads into this.

Additionally, the definitions of the therapeutic relationship above, do not consider the environment, for example, the resources available, within the relationship, that facilitate the direction and which affect how the patient in rehabilitation and therapist make a connection. From the perspective of this current research, these include the availability of the staff, the skills-in-use by the staff, the practical effect of many therapists and support staff working with each client and the policies and procedures in use within the organisation. For example, in this current research policies relating to the length of time a person should be in the rehabilitation unit probably affected the discharge date of one of the participants. When the practitioners thought the improvement was slowing, the participant was encouraged to go home as discussed in chapter ten (Relationships). The resources in a therapeutic relationship should also include the abilities and disabilities of the patients in terms of their rehabilitation.

This type of complexity in the relationships between the participants and the staff, the rehabilitation environment and the effects on involvement and outcomes, should be the subject of further study, perhaps within a critical theory epistemology.

In the current research, the participants developed relationships with a number of staff from a range of professional disciplines, for example, physiotherapists, occupational therapists and nurses who were from different social and educational backgrounds. Though the development of relationships was continuous and changeable, for ease of discussion, the developing relationships were divided into three types: paternalism, collaboration and partnership, chapter ten (Relationships Table 10.7). Paternalism was evident within the relationships between the staff and the participants throughout the data collection-analysis period, (Table 10.7 see also Appendix Two the extract from a conversation narrative). Paternalism was especially evident early in rehabilitation, when the participants' cognitive understanding of rehabilitation and physical ability were reduced. This paternalism led to compliance and personal weaker risk management strategies.

Although, paternalism has been reported to reduce involvement (McGrath and Davis, 1992, Schut and Stam, 1994), arguably, it is more appropriate, early in rehabilitation, as part of the assessment approach, managed through operant learning. Conversely, this early period of rehabilitation is a formative time when people will have already started to develop their Involvement Attributes (Figure 5.1). A more collaborative approach may have set the scene for an appropriate Vision, and Goals Disposition, a Cognitive Learning strategy and a personal Risk Management strategy. Collectively this would increase involvement.

A paternalistic approach has been reported in other studies, for example, Talvitie and Reunanen (2002) who used discourse analyses of recorded clinical sessions to describe the type of interaction between physiotherapists and their patients. One of the important conclusions from this research, suggestive of paternalism, was that

> “Patients were allowed little opportunity to take the initiative in their treatment and had difficulty in being treated with consideration and being understood” (p86).

This paternalistic relationship may well reduce involvement through a reduction of the Involvement Attribute set.

In this current research it was the participants’ management of paternalism that demonstrated particular levels of involvement. Although overall, the participants accepted the paternalistic approach within their rehabilitation, especially in the early stages, their reactions were: acceptance, acceptance with surprise and concern, and acceptance with tolerance (Table 10.7). Where there was full acceptance of paternalism, (this participant had weak, balanced and aligned Involvement Attributes) the relationship was led by the staff and the staff seemed to expect this response. This was a similar finding to the work of Talvitie and Reunanen (2002).

The second reaction, surprise and concern occurred when there was surprise because the paternalism was unexpected and concern because the participants were not used to this approach (this person had strong imbalanced and misaligned Involvement Attributes). This concern reduced over time, and moved towards acceptance. This acceptance weakened her Involvement Attribute set, may have prevented her discussing her covert goals and facilitated a misalignment of her Vision and Incentive and Goals. In another participant, acceptance of paternalism facilitated personal goal achievement. This last type of acceptance demonstrated tolerance, which occurred where the participant thought that temporary acceptance was necessary, given the need for physical help. This tolerance did not affect the Involvement Attribute set and involvement remained strong.

The constructions in this current research were similar to other research (McGrath and Davis, 1992, Schut and Stam, 1994). Where the approach by the staff was paternalistic involvement was weaker than when less power was exerted by the staff. For example, Joe let the physiotherapists lead and made no decisions, but he demonstrated stronger involvement when he suggested to the support nursing staff, that he should use a Zimmer frame rather than be pushed in a wheelchair, discussed in Chapter ten (Relationships - *Divergence*). With this second group Joe demonstrated that he was cognitively learning about the changing levels of his impairments which strengthened his Involvement Attribute set and improved some of the imbalance in that respect.

Within the research literature there is some evidence that a more equal power balance than that provided by a paternalistic approach is preferable in a therapeutic relationship. For example May (2001) used a descriptive design to analyse data from 34 patients with back pain considering satisfaction of the patient. One of the themes within patient satisfaction was that the patients needed to be listened to and that the treatment was seen to be a consultative, rather than a prescriptive process. Additionally, Potter et al (2003) concluded that physiotherapists should actively involve their patients in their management seeking a person-centred approach to physiotherapy.

This active involvement is suggestive of a partnership relationship. From this current research this will have a beneficial effect on the Involvement Attribute set.

In this current research, changes in relationships were not solely paternalistic and they were not just with the staff of the Intermediate Care unit. Important relationships were also demonstrated with the relatives of the participants. In these relationships there were examples of collaboration with relatives who brought in food, or other items, that helped in the rehabilitation or for comfort. However, the relatives were not participants in this research and their effect on the Involvement Attribute set of the participants is unknown.

Some of the staff, some of the time, worked collaboratively with the participants. As they worked collaboratively with the participants, if the Involvement Attributes were increased the involvement in rehabilitation would also be increased. This could be tested in further research.

According to Freire (1970) the social environment is led by the exertion of power.

> “From this submission was born a consequent adjustment; accommodation rather than integration. Accommodation requires a minimal dose of critique. Integration, on the contrary, demands a maximum of reason and consciousness” p69).

Friere (1970) is suggesting that for integration there is a role for both the patients and staff in facilitating a partnership relationship. This is significant in a multidisciplinary process, such as rehabilitation, as it seems difficult to marry the notion of a consistent collaborative approach in rehabilitation with the concept of being managed by different staff, of different professional and social backgrounds (Tresolini and The Pew-Fetzer Task Force, 1994). Additionally, the person in rehabilitation must take some responsibility in the relationship. This responsibility was discussed by Young and Resnick (2009) whose work was outlined in chapter three (Literature review page 58). Young and Resnick (2009) reported that patient attributes, similar to the constructions in this thesis, played significant roles in making rehabilitation work. These attributes were self-determination, a positive attitude, social support and full engagement in recommended rehabilitation activities. The nature of involvement has been conceptualised and described in this current research and this may relate to “full engagement” described by Resnick (2009). This notion of responsibility is also supported by Hawley (2009), (discussed in chapter three, Literature Review page 62) who associated patients’ desire for independence and the need for relationships with staff and families with the continuation of rehabilitation at home.

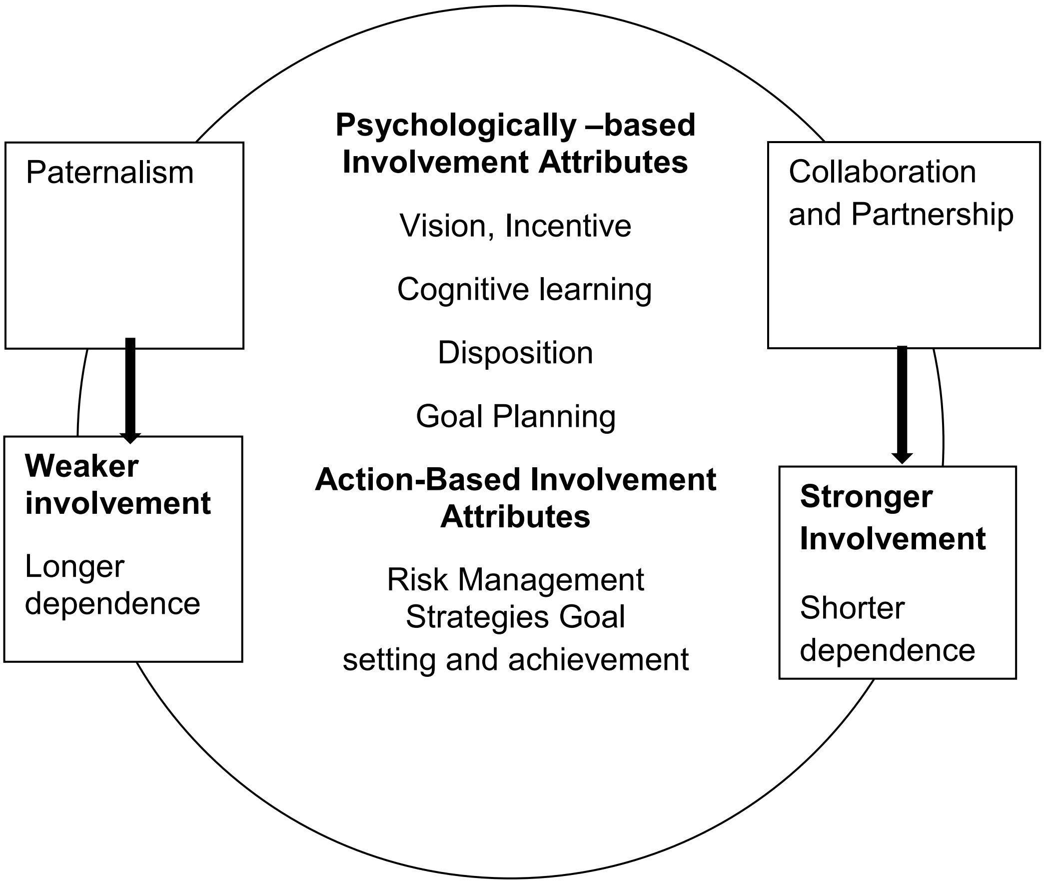
In this current research, the therapeutic relationship was rarely led by the participants. When they provided personal solutions to potential barriers to their comfort or progress it could be argued that they were adding value to the rehabilitation regime (Risk management this chapter) but not overtly determining a relationship. The significance of this is that with a more robust Involvement Attribute set a participant will be able to take more from a facilitative therapeutic relationship and demonstrate responsibility.

In their literature review, Kuokkanen and Leino-Kilpi (2000) suggested that there should be a joint commitment to power sharing. From a wider, social perspective this joint commitment might be useful, as the idea of collectivism in health care continues to move in the direction of consumerism (chapter two, Background). However, from this current research and the research literature, a joint commitment to power sharing is far from universally practiced.

From the constructions of this current research, a move away from paternalism towards partnership is likely to make the Involvement Attribute set more robust and so increase involvement. Where paternalism dominates the Involvement Attributes are likely to be weaker which effects reduced involvement. Weaker Involvement Attributes may increase dependence and so rehabilitation outcomes may be poorer.

There is some evidence from this current research that partnership relationships strengthen the Involvement Attributes and so increase involvement. Where psychological independence is facilitated, as in collaborative and partnership relationships, the Involvement Attribute set will be made more robust and involvement is likely to be stronger, dependence shorter and the outcomes may be richer. Figure 11.4 summarises the relationship between different therapeutic approaches and involvement. This should be tested in further research.

Figure 11.4. A Summary of the Relationship between Different Therapeutic Approaches (Relationships) and Involvement



However, partnership relationships in rehabilitation can be complex and fragile. The complexity and fragility is concerned with the changing situation in rehabilitation, for example the changing functional abilities of the patients over time, the different staff who attend them and other factors in the environment of the rehabilitation, such as policies and procedures that are followed.

The Association of the Meaning of Involvement to the Wider Social Context

Although this current research has produced a stand-alone theory about the meaning of involvement, the constructions can be associated with social theory. This next section discusses this association.

Outcome Expectancy Theory

Some parts of involvement can be explained by outcome expectancy theories, the acquisition of expectancies that certain actions will lead to desired outcomes. Outcomes can be physical, social, positive and negative and are moderated, within capabilities, by a positive and negative self-evaluation of a person's behaviour (Bandura, 1986). From the constructions in this current research, two types of outcome expectations were displayed. The first type of these outcome expectations was the goal to go home. In this current research the time of discharge (going home) was decided externally, primarily by the multi-disciplinary team. The second type was self-evaluative and depended on personal performance, such as to increase stamina, or to organise aspects of care. These were often managed by the participant themselves.

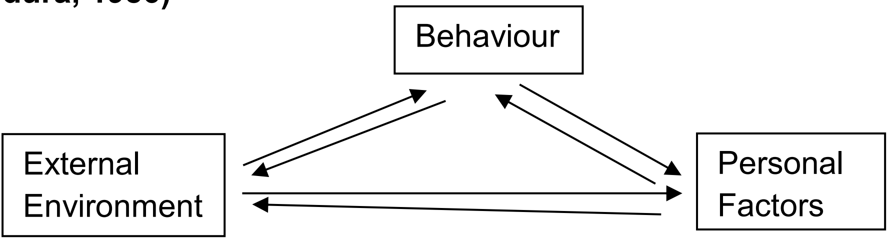
Involvement incorporates these two types of outcome, but is not explained entirely by this. Although outcome expectancy theories are part of the constructions and relate to the individual through the Involvement Attribute set, they do not include the interaction with the environment through the relationships within rehabilitation and so do not fully encompass the meaning of involvement.

Other theories about aspects of involvement constructed in this research such as motivation also do not seem to have the social breadth to encompass the meaning of involvement. For example, motivation towards the achievement of goals in rehabilitation has been known to be important for many years (Fordyce, 1976). However, involvement in rehabilitation is not only about the motivation to succeed. Involvement is concerned with the *process* of interaction between the personal attributes of both the person in rehabilitation and the staff, over a period of time. Social theory that could encompass involvement must include the personal attributes of the people and take account of the interactions between patients and staff in the rehabilitation environment.

Social Cognitive Theory and the Triadic Reciprocal Causation Model

The rehabilitation environment, which includes relationships, is taken into account within Social Cognitive Theory (Bandura, 1989, Bandura, 1982, Zulkosky, 2009). Social Cognitive Theory suggests that people are not independent and autonomous in their thoughts and actions, but live complex interdependent lives and make choices depending on the environment in which they live. This is congruent with symbolic interactionism (discussed in chapter four, Theoretical Framework and Method, (Mead, 1962, Blumer, 1969)). Within Social Cognitive Theory the Triadic, Reciprocal Causation Model (Bandura, 1986) postulates that humans relate towards each other within three inter-related determinants, which have a reciprocal effect. These three classes of determinants are behaviour, internal personal factors, in the form of cognitive, biological and affective events and the external environment Figure 11.5.

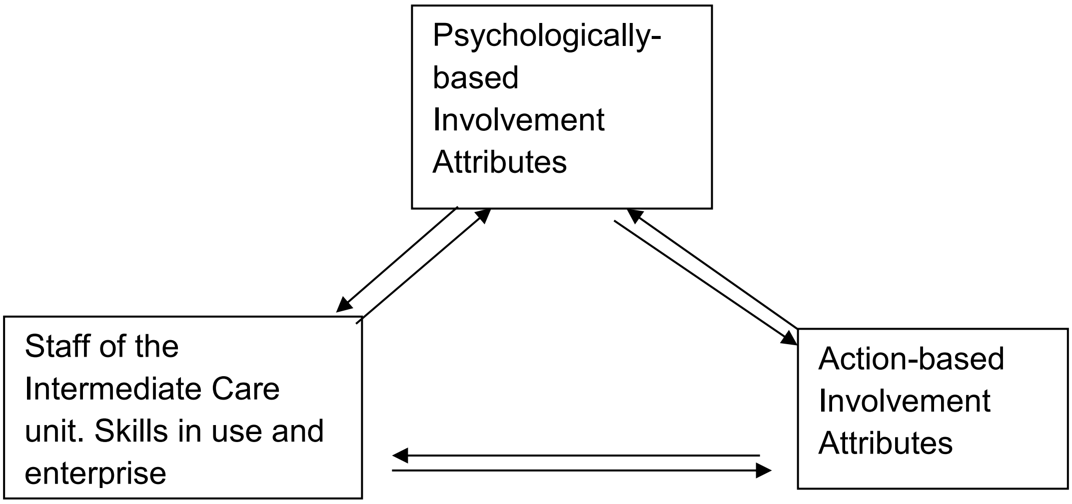
Figure 11.5 A Representation of the Triadic Reciprocal Causation Model (Bandura, 1986)



The Triadic Reciprocal Causation Model (Bandura, 1986) suggests that the way the participants behave in rehabilitation, influenced by the individual's relevant personal factors, is determined by, and determines, the social environment in which rehabilitation takes place.

Within the limits of this current research, the Theory of Involvement can be mapped on to the Triadic Reciprocal Causation Model (Bandura 1986). The personal factors include the psychologically-based Involvement Attributes, the behaviour includes the action-based Involvement Attributes and the external environment is concerned with the skills-in-use and enterprise of the staff as the patients' Involvement Attribute set becomes stronger (Figure 11.6). This can be used to show that Involvement is concerned with all stakeholders reciprocally.

Figure 11.6 Mapping the Theory of Involvement on to the Triadic Reciprocal Causation Model



Determination of the environment is managed through human agency (Bandura, 1997). Human agency is the ability to determine the environment, by exercising options in decision-making within an environment at a particular time (Bandura, 1997). Although there are many social rules and facts that an individual has no control over (Musolf, 2003), people operate within the social environment at a level of human agency, working in the environment through reflexive action rather than responding to external stimuli alone.

In the context of this current research, the possession of a robust Involvement Attribute set provides the means of reflexive action and so influences human agency reciprocally with the staff. Participants involved in rehabilitation develop human agency through an increasing understanding of collective meanings about themselves and their environment within relationships and are enthused to act to progress in rehabilitation. In a similar way that Mead (1932) and Blumer (1969) explain symbolic interactionism and Gadamer (1995) explains understanding, Bandura (1997) suggests that it is through a common understanding of meaning and the relationships with people that this affords, that human agency is effected.

Paternalistic relationships, where the paternalism comes from the staff, are more determining for those in rehabilitation than collaborative and partnership relationships (Hughes et al, 2008). In this current research, those who were most involved, that is had a strong, balanced and aligned Involvement Attribute set, were more determining in their relationships and tolerated paternalism. Those whose Involvement Attribute set was less robust were more determined by the social environment of the Intermediate Care unit and were less involved. This further indicates the important role that therapeutic relationships play in rehabilitation.

Another way of describing human agency is the ability to externalise personal attributes and internal determinants such as motivation and mood, into action. In the case of rehabilitation this means making progress. A measure of this, at an individual level, is self-efficacy, a measure of how well a person can make choices and move these choices forward in prospective situations (Bandura, 1982).

Although levels of self-efficacy were not measured in this current research, higher levels of apparent self-efficacy were associated with stronger levels of involvement, as in these cases, the individual acted to become more determining rather than determined. This occurred where the Involvement Attributes were strong, balanced and aligned. A possible hypothesis is

> Those who are able to demonstrate strong, balanced and aligned Involvement Attributes within rehabilitation relationships have higher levels of self-efficacy, which leads to better outcomes in rehabilitation.

However, although involvement is related to self-efficacy, it is not the same thing. Self-efficacy requires a domain, for example, rehabilitation, and is therefore an attribute possessed by an individual that supports the confidence for them to act in specific circumstances (Bandura, 1986). Self-efficacy measurement scales, measure the self-efficacy of the individual in specific circumstances at a particular time, in a particular domain, but take no account of the nature of the relationship with the staff at that time (Bandura, 2006). The therapeutic relationship is important in involvement because the nature of the relationship can alter the level of self-efficacy, through vicarious experience and verbal persuasion, influencing the level of involvement and the outcomes of rehabilitation (Schwarzer, 1992). From this current research the therapeutic relationship is important in the demonstration of the Involvement Attributes in rehabilitation and defines a difference between self-efficacy and human agency, and involvement.

The definition of involvement, provided at the beginning of this chapter only took into account the position of the person in rehabilitation. When therapeutic relationships are taken into account the definition becomes

> "A joint commitment within therapeutic relationships to determine and be determined in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

This can be used by staff who *centre* the care and rehabilitation on partnership relationships within a care framework that considers the person in rehabilitation holistically.

Person-centred care

Person-centred care is concerned with moving the emphasis of care towards the person in an holistic manner. The conceptual understanding of person-centred care has been discussed in detail in chapter three (Literature Review). The Involvement Attribute set constructed in this current research, discussed in chapter five (Constructions pages 174-177) and chapter ten (Relationships pages 289-297) suggests that the adoption of a person-centred care framework will assist in the development of the Involvement Attribute Set of people in rehabilitation. The development of the Involvement Attribute set would occur through facilitation of the authentic, prospective voice of the person (McCormack, 2003, McCormack et al., 2010b). Facilitating that authentic voice entails knowing the patient in their world (Clarke et al., 2003, Slater and McCormack, 2005) and a sharing of knowledge founded on mutual trust and understanding (McCormack, 2003, Gzil et al., 2007) within an aspiration to form new relationships thought to be useful in the care of older people (McCormack, 2003, McCormack, 2004, Department of Health, 2001b, Department of Health, 2000, Dewing, 2004) and in rehabilitation (Gzil et al., 2007). Person-centred care is also likely to facilitate involvement, as it is defined in this current research, as it recognises the Triadic Reciprocal Causation Model (Bandura, 1986) discussed above, by accepting the interdependence of all the stakeholders in health care interactions. It is suggested, therefore, that involvement, as defined in this research, is a component of person-centred care and th Triadic Reciprocal Causation Model .

Conclusion to the Constructions and Study Discussion.

This research has constructed a sophisticated meaning of involvement for older people in their rehabilitation after acute illness which explains involvement in rehabilitation and may be able to be used to predict involvement in the future. The meaning of involvement, in the context of this current research, consists of the use of four, interdependent, Involvement Attributes, which were constructed from the analyses, discussed in chapters five to ten and expressed in diagrammatic form in Figures 5.1 and 10.1. These are a Vision and Incentive for the future which, together with Cognitive Development and a positive Disposition, lead to Goal planning, setting and achievement and personally owned Risk Management strategies and actions. The Involvement Attributes are managed within relationships with health care staff and relatives in a health care environment. Collectively, the Involvement Attributes are Attributes that facilitate Involvement to achieve goals within relationships with health care staff.

The association of the Involvement Attributes, with the Reciprocal Triadic Causation Model (Bandura 1986) and person-centred care (McCance et al., 2011, McCormack, 2001, McCormack, 2003) suggests that to be maximally involved people in rehabilitation must be or become, determining in a facilitative partnership therapeutic relationship. From this current research that determination should be directed towards the acquisition and use of a robust set of Involvement Attributes, strong, balanced and aligned. However, people in rehabilitation cannot be determining alone, involvement in rehabilitation requires a relationship and a facilitative environment. This current research suggests that it is this person-centred relationship that provides a key to increasing levels of involvement in direct care.

The rehabilitation staff also determine the relationship with those in rehabilitation. Staff are the best placed, through skills-in-use and enterprise, to facilitate improved strength, balance and alignment of the Involvement Attributes within therapeutic relationships and the clinical and managerial environment. The skills-in-use and enterprise include the management of appropriate relationships within a facilitative, for example a person-centred care framework, incorporating a move away from paternalism.

These three components, the Involvement Attributes of the people in rehabilitation, the skills-in use and enterprise of the clinical staff and facilitative therapeutic relationships within the clinical and managerial environments may need to be managed flexibly in order to strengthen the Involvement Attribute sets of those in rehabilitation.

Within facilitative therapeutic relationships, people in rehabilitation must also be guided and assisted by health care by staff who are able to work with the individuality of their patients and be prepared to be determined by them in their health care role. The guidance, assistance and facilitation may be grouped together and called the determining role of the staff. The people in rehabilitation must be ready to take responsibility, to make decisions and to learn and work, both physically and emotionally, both inside and outside the therapeutic relationship. When this occurs the people in rehabilitation are also determining. Summarising the relationship between people in rehabilitation and health care staff through the mutual pursuit of an Involvement Attribute Set (Figure 11.2) it is suggested that neither a person in rehabilitation, nor a member of the health care staff can be involved in rehabilitation on their own and achieve the maximum benefit. Involvement for older people in their rehabilitation is therefore

> "A joint commitment within therapeutic relationships to determine and be determined in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

Chapter Twelve: Conclusion to the Thesis

Introduction

This last chapter discusses three main issues. The first is the research itself concerned with the academic contribution, trustworthiness and limitations of the thesis. The second issue concerns the organisational implications and recommendations and further research. This second issue fulfils the second aim of the current research. The third issue is a conclusion to the thesis which briefly links the beginning middle and end of the thesis.

The Academic Contribution of the Thesis

Different types of health care involvement have been described in terms of involvement in health care planning, evaluation and in direct care, (Tritter 2009). Different types of agency relating to people taking part in rehabilitation, have been described (Christiansen and Townsend, 2004, Kjerski et al., 2008). Additionally, concept analyses on similar words to involvement, such as participation, have been completed (Sahlsten et al., 2008a, Hook, 2006). However, the meaning of involvement in direct health care still requires attention (Coulter, 2011, Fudge et al., 2007, Forbat et al., 2009). Without clarity of understanding and use, any benefit from involvement cannot be maximised.

This thesis proposes that for older people in rehabilitation after acute illness involvement is managed through a set of Involvement Attributes. This Involvement Attribute set is divided into two groups. These groups are the psychologically-based and action-based Involvement Attributes. The psychologically-based group consists of Vision and Incentive and Goals (planning), Cognitive Development and Disposition. The action-based group consists of Risk management and Goals (setting and achievement). Goals therefore span the two groups.

Vision and Incentive refers to the possession of a vision of life after rehabilitation, for example, to want to go home as independent as possible and an incentive to achieve the vision, for example, to be with family. Closely associated with the Vision and Incentive are *Goals* (planning) these are extensions of the Vision and Incentive and give the Vision and Incentive direction. A positive *Disposition* in rehabilitation is concerned with Motivation, enthusiasm and hope and *Cognitive Development* facilitates learning and the adaption of that learning to suit the person in rehabilitation. Risk Management refers to the decisions and management of uncertainty concerned with taking and avoiding risk. These risks are associated with Goal setting and Goal achievement.

The psychological Involvement Attributes drive the more action-based Involvement Attributes *goal, setting* and personally owned *Risk Management* strategies concerned with decision-making and *goal achievement*.

To be maximally involved the two groups of Involvement Attributes have to be strong, balanced and aligned. This produces a robust Involvement Attribute set required for strong involvement.

People working with their own Involvement Attribute set operate through relationships in rehabilitation and are both determined and determining within these relationships. Within relationships there are therefore opportunities to improve the Involvement Attribute set or cause deterioration.

The Theory of Involvement increases the clarity of understanding of involvement in rehabilitation. Increased clarity understanding will provide opportunities for practitioners and their support staff and their patients to recognise and promote involvement within relationships developed during rehabilitation.

The Strengths of the Research Design

The meaning of involvement, constructed in this current research, is grounded in the relationships that the participants developed with the staff of the Intermediate Care unit. It is these relationships that the methodology of grounded theory, through pragmatism and symbolic interactionism, was designed to explore. However, it could be argued that the acceptance of the primacy of symbolic interactionism associated with grounded theory increases the likelihood that relationships came out as the overarching conceptual category. It can equally be argued that, in this exploratory study, an open mind and the desire to learn, associated with the features of grounded theory, is well placed to facilitate the constructions of this research. In terms of research context, the data were collected in a linear manner, from participant one to four, within one Intermediate Care unit, over a short period of time. This provided a relatively stable organisation culture with static working practices within which the relationships between the older participants and the staff could be compared. This part of the research design, meant that each participant followed similar rehabilitation processes, developed from the same umbrella of resources, including the provision of information.

The length of rehabilitation and the older people's progression through the Intermediate Care unit provided opportunities to collect a longitudinal "chain of evidence" (Yin, 1999) about the individual nature of the participant's rehabilitation stay. In terms of the research processes, the constant comparison of the data throughout the data collection-analysis procedure, from the open coding to the development of conceptual categories, facilitated the holistic development of a sophisticated understanding of the meaning of involvement within rehabilitation. The data collection-analysis process led to a cross-case comparison of the four older people participants which was pivotal to the development of the conceptual categories, the Involvement Attributes, and the Theory of Involvement.

All the participants required rehabilitation after an acute illness and so had many of the same needs, for example, rehabilitation was required after prolonged bed rest. The advantages of researching the meaning of involvement in this narrow field of work outweighed the advantage which might have been gained by use of different types of rehabilitation cases. The advantage occurs because the reason for the participants' requirement for rehabilitation was not as important as how the participants managed their progression in rehabilitation. Concentration on the management of progression rather than ability improvement facilitated the subordination of the conceptual category “Functional Development”. The subordination of the context from the meaning of involvement increases the opportunity for transferability of the results to other contexts. This is discussed in the transferability section below.

Other strengths of the research design included the general facilitation within the management culture of the Intermediate Care unit, which assisted in the development of an understanding about how the Intermediate Care unit was managed and provided practical facilitation in the recruitment of participants. The practical facilitation extended to access to the weekly multi-disciplinary team meetings. Attendance at these weekly team meetings facilitated talking to occupational therapists, physiotherapists, nurses and medical practitioners before the start of, and during, the research. Suitable participants, introductions and difficulties (such as levels of wellness, mental capacity and admission and projected discharge dates) were discussed at these and other meetings, some of which occurred on a daily basis.

The Trustworthiness of the Research

The goal of this research, in relation to trustworthiness, was to accurately represent the participants’ experiences during rehabilitation related to the experiences of the staff who worked with them in this prospective study. Trustworthiness was approached using Credibility, Dependability, Confirmability and Transferability (Guba and Lincoln, 1994, Streubert and Carpenter, 1999).

Credibility

Credibility is the likelihood that the constructions presented reflect the experiences of the participants. Credibility is therefore a judgement of others. In this current research “others” refers to the participants, the older people and staff who were involved in the research and the social scientific community. It was important to plan the capture of the views of the older people about the credibility of the research as the research progressed. After the data collection-analysis period the older people would be unable to be contacted.

The Credibility of the current research was increased in three ways: firstly, by interviewing the same participants, at different times, over an extended period. This is summarised in Tables 4.5, 4.6, 4.7 and 4.8. As each interview or conversation was completed, the recording was used to develop the questions for future interviews with both practitioners and participants, as summarised in Table 4.9 and presented in Appendix Twelve. Secondly, it was increased by discussing issues and leads that participants (both older people and staff) reported in previous interviews. Thirdly, it was increased by checking the developing constructions with the participant during the interview period, (see examples of the indicative questions asked in Appendix Twelve). The developing constructions were also discussed with more objective health care practitioners who had an interest in rehabilitation, as suggested by Glaser and Strauss (1967).

Dependability

The dependability of the research was increased by the maintenance of an audit trail throughout the research. This was organised from the beginning of the research, so that all aspects of the research could be referred to as required. Before commencing data collection important documents, such as the research and ethics approval letter from the National Research Ethics Service were kept (Appendix Six). In terms of data collection the recordings and transcripts were kept. Each line of the interview and conversation transcripts was numbered and the use of these line numbers were organised through the transcript identification system outlined in chapter four (Theoretical Framework and Method) an extract of an example of this is presented in Appendix Two. *Post*-data collection, a record of the analysis process was kept, which is demonstrated in four ways. Firstly, through coding, examples of open codes are presented in Appendix Thirteen and examples of axial codes are presented in Appendix Fourteen. Secondly, by the production of early diagrams used in the constructions (Appendix Fifteen) and thirdly, by the production of tables for example the Cross-Case comparisons (Appendix sixteen). Lastly, dependability was demonstrated by keeping records about the research that demonstrated step changes in the thinking about the data in the form of “Out Of The Blue” ideas (examples at Appendix Seventeen).

Confirmability

This measure of trustworthiness is concerned with a demonstration that the researcher has acted in good faith and produced constructions that are true to the data and not overtly influenced and unchecked by the personal values of the researcher (Bryman, 2008). Confirmability is another audit trail, closely associated with dependability, articulated here as the reasoning behind the decisions made in the construction of the meaning of involvement. The difference between dependability and confirmability is, therefore, where dependability is concerned with the audit of a paper trail, confirmability is concerned with a trail of the thought processes of the researcher that led to the final constructions and conclusions.

Examples of thought processes in this current research that increased the Confirmability in this research were the ideas that came from the Cross-Case comparison (Appendix Sixteen) as different levels of involvement were demonstrated by the different participants. Other examples include the development of the relationship between the original six conceptual categories Figure 5.1, the realisation that "Functional Development" was peripheral to the four Involvement Attributes and that the Vision and Incentive was integral to Involvement.

Transferability

The level of transferability of research findings is an estimate of the potential that if the same methodology and method were used in another setting or the same setting at another time, the same conclusions would be constructed. This is useful as the higher the level of transferability the more useful the conclusions. Although transferability is for others to judge, it is important that the judges have sufficient information in the research to make a judgement. In this current research, a thick description (Geertz, 1973) of the research context, a detailed description of the methodology and method and articulation of the constructions and conclusions, serves to increase the ability of others to judge the transferability.

After testing the theory of Involvement the clarity and understanding that this provides may be useful in contexts other than rehabilitation, for example, in developing care strategies in Nursing Homes and in managing the care in some forms of mental illness. It may be possible to increase confidence in this through an action research project designed to build partnership relationships and develop the Involvement Attributes in the patients and staff. Transferability should be tested, which is a recommendation for future research.

The Limitations of the Research

Ontological issues

This current research presents a substantive grounded theory about the meaning of involvement for older people in their rehabilitation after acute illness. The relativist ontological basis of this social theory reduces its apparent transferability without further testing. Further testing will increase the confidence of the constructions and any concerns about data saturation (Morse, 1995) and data sufficiency (Dey, 1999) by increasing the sample size discussed in chapter four (Theoretical Framework and Method).

Epistemological issues

In chapter four (Theoretical Framework and Method), the choice between a Constructivist and a Critical Theory epistemology was discussed. A critical theory methodology was dismissed on the grounds that the objective of the research was to develop a substantive theory about one part of the community life of the Intermediate Care unit. The development of a substantive theory was effected by sampling actors taking part in a joint effort to reduce the impairments of the older people, or to find ways of reducing the effects of the impairments. Consequently, the research was based within symbolic interactionism and designed to capture data about the nature of involvement rather than the reasons why involvement occurs.

At the time it was realised that this approach would underplay the role of the social structure, particularly power relations and the reasons for the behaviour demonstrated within the rehabilitation environment. However, *a posteriori,* it is even clearer that this current research leaves a gap in the research analysis. This gap is related to the social structure and power relations within the Intermediate Care unit (Tang and Anderson, 1999) in favour of the staff. These power relations were highlighted by Holen and Ahrenkiel (2011) who discussed three positions of responsibility of patients for their illness, in a Norwegian hospital, in terms of the relationship between neo-liberalism and medical discourses. Additionally Ward (2012) recognised his position of power as a doctor in medical discourses in rehabilitation. It will be possible to use the current research, in further study within a critical theory epistemology, to understand how social structure and power relations affects the Involvement Attributes in rehabilitation.

It is also acknowledged that the data represents the views of a small community rather than the views of all the people in the Intermediate Care service. One way to increase the breadth of the current research would have been to use an ethnographic approach taking on the role as a member of staff or as an observer. The choice not to do an ethnographic study was based on the small size of the Intermediate Care unit, and the negative effect this might have on the vocal and behavioural gestures of the participants. This negative effect might have occurred because the researcher was known to some of the staff prior to the commencement of the research.

Methodolological Issues

Some participants' functional abilities developed quickly so, to map their progression and changes, the interval between interviews was necessarily short. The requirement for a quick succession of interviews was, therefore, a function of the nature and duration of rehabilitation. To reduce the effect of this, the data for Participant One and then Participants One and Two were analysed fully before the research progressed and Participants Three and Four were recruited (Tables 4.5-4.8). The analyses from each of the participants informed the next, cumulatively through the recruitment interview based on a judgement of the potential participants' aspiration for their rehabilitation.

Method Issues

The constructions and substantive theory are dependent on the sampling techniques, the data collection methods and the interpretations of the investigator. It may have been possible to strengthen the constructions by involving older people, with similar rehabilitation issues to the participants, and staff in the design of the research and more overtly in the interpretations of the data. However, this would have increased the time required by both the older people and the staff which may have affected their responses. For example, there would be far more opportunities for the older people and the staff to learn from each other about the nature of involvement as the data collection progressed. The way this research was managed, this cross referencing was formally reduced so improving the breadth of the data.

There were several older people who refused to take part in the research for reasons known only to themselves. In *post*-positivist research, where the phenomena under investigation are thought to be unrelated to the social research context, recruitment of another participant after refusal is acceptable. This is because the empirical research is not concerned with interpretation and construction and more concerned with generalised discoveries. In this current research, where observations are accepted to be interpretations of the social world, analyses that omit data that might have come from someone who refused to take part, for example, because they were angry, are important. The analysis of data from those who did not want to take part in this study may have added further dimensions to the meaning of involvement. In further studies, it may be possible to capture this type of data in less intense ways through focus groups and questionnaires devised from the results of the current research.

The Clinical and Organisational Implications and Recommendations as a Result of the Research

Organisational Implications

The clinical and organisational implications of this current research centre on the notion that it is difficult to consider increasing patient involvement in their care and rehabilitation without considering reciprocal changes in the approach of the staff and the environment in which the rehabilitation takes place. If patient involvement is to improve, this current research suggests that changes in those receiving rehabilitation and those working with them need to develop together. The clear associations of the Theory of Involvement with person-centred care and the understanding that older people both determine and are determined by the relationships with staff imply that the culture and context of rehabilitation is also important in the involvement of older people in their rehabilitation.

Efforts to increase involvement might commence, on the staff side, with different, more humanistic, cohesive working practices. These practices include approaches to patients which recognise and use the Involvement Attributes to increase involvement. From an organisational perspective this would require a transition away from paternalistic rehabilitation towards that of collaboration and partnership with people in rehabilitation and their families operating from the perspective of person-centred care. However, these structural and process changes will require strong leadership and a supportive managerial imperative. Additionally, careful planning and achievement over a period of time is required so that staff become effective in these approaches to their work. Some of the planning for this development is incorporated into the recommendations, below, which may be managed through Action Research and Appreciative Enquiry approaches.

Recommendations

- There are some structural and process changes that would facilitate a change in relationship away from paternalism towards collaboration and partnership within relationship-centred care. Four suggestions are made that would facilitate different approaches by the staff and patients. All four suggestions are concerned with actions by the staff occurring within the relationships with those in rehabilitation. However, the suggestions simultaneously reach out to those in rehabilitation attempting to develop their cognition and behaviour in rehabilitation. The suggestions are:
- the adoption of the Involvement Attributes as a framework for assessment, prospective development, evaluation and prognosis.
- increasing *Cognitive Development opportunities*
- improving the consistency of approach to those in rehabilitation and
- The adoption of person-centred care as a framework for rehabilitation and through this the encouragement of the involvement of relatives and friends in rehabilitation.

Adoption of the Involvement Attributes as a Framework for Assessment, Evaluation and prognosis

The first recommendation of this current research is to use the Involvement Attributes to predict, assess, prospectively develop and evaluate rehabilitation progress. For example, assessment could be made of the person's Vision and Incentive how this aligns with their physical abilities. Goal planning, setting and achievement could be measured against the four types of goal and the level of hope and personally owned Risk Management strategies could be assessed. Overall the Involvement Attributes could be used by the staff and those in rehabilitation to:

- Assess how individual people might become involved in their rehabilitation, their rehabilitation potential and how involvement may be increased.
- Plan and implement a programme of rehabilitation which includes psychologically-based and action-based goals incorporating and encouraging the strength, balance and alignment of the Involvement Attributes.
- Evaluate how resources within the Intermediate Care unit influence people in their rehabilitation and how these can be reorganised to improve the level of involvement. For example, some people like to work and learn on their own whilst others would prefer group work.

Increasing Cognitive Development Opportunities

This could be done through developing a learning culture within rehabilitation which promotes Cognitive Development. This venture should not be concerned with the provision of information in paternalistic way, but in a person-centred way that promotes and develops the responsibility of the person in rehabilitation and operates in ways that suit them. For example, it is known that group learning is beneficial and this form of information provision promotes Cognitive Development (Payne, 1991, Payne, 1995, Schouten et al., 2011). This might be used to assess learning styles. Other ways of promoting Cognitive Development include the provision of information through discussion with people who have been through the rehabilitation system. Reading material, such as pamphlets and books could be treated in the same way. The important issue is to facilitate cognitive learning rather than deliver information. Discussion and questioning around individual circumstances will assist with this, particularly amongst older people in rehabilitation, their family and friends. The use of film to demonstrate exercises and DVDs of other people's progression through rehabilitation may also promote discussion. These ideas are not exhaustive and there are many other ways to promote Cognitive Development suited to individual people.

Improving the Consistency of Approach to Those in Rehabilitation

One issue in developing consistent relationships that would facilitate improvement in the Involvement Attributes is to reduce the perspectives, and therefore the number distinct approaches to rehabilitation. A more consistent approach to rehabilitation and care could be achieved over time through making the approaches to rehabilitation more transparent within the rehabilitation culture, whilst maintaining an open disposition to development. In much the same way as the older people in rehabilitation are expected to change, so the staff should be expected to change towards a more cohesive relational approach that integrates the personhood and person-centred care into rehabilitation work.

The Adoption of a Person-centred Framework for Rehabilitation and through this the Encouragement of Relatives and Friends in Rehabilitation

In this current research, although the presence of relatives and friends were officially welcomed, the part they played in the rehabilitation of the older person, such as bringing in food and other comforts and organising the home on discharge, was hidden from the mainstream work. The work of friends and relatives went unrecognised as part of the standard rehabilitation process. The contention is that a more substantial role for relatives is useful and should be assessed. Not all relatives or friends will want to be involved in the rehabilitation in a substantial way. However, one way of encouraging people to take more responsibility for their health care in the future is to involve them in terms of the Involvement Attributes. Additionally, some relatives and friends will be part of the personhood of the older people in rehabilitation. This should be taken into account within the broad remit of person-centred care .

Suggestions for Further Research

Testing the Theory

The Theory of Involvement hinges on the role of the Involvement Attributes to explain and predict involvement. The first test would be to find out, qualitatively, how useful the Involvement Attributes are in health care practice. This might be done through an action research project based within appreciative enquiry and incorporate the recommendations of this current research. Following this, using a realist ontology and *post*-positivist epistemology, testing should be concerned with finding, adapting or devising measurement tools for the Involvement Attributes and involvement itself. The involvement theory could then be tested by introducing elements of rehabilitation or ways of working designed to strengthen, balance and align the Involvement Attributes to increase involvement.

The results of the research should be tested first in similar contexts such as other Intermediate Care units and armed forces rehabilitation units to see if the constructions hold true. Following this, testing should be done in dissimilar contexts. Dissimilar contexts include palliative care situations in hospices, training situations on practically based health care courses and living conditions in long-term Residential and Nursing Homes. In these studies, it may be possible to capture data from a wider range of people through, for example focus groups and questionnaires. Using a critical realist ontology, one nul-hypothesis, on which to base the testing is:

> The benefits and disbenefits of rehabilitation based on a collaborative, partnership managed through the management of the Involvement

> Attributes do not outweigh the benefits and disbenefits of rehabilitation based on usual ways of working.

A further test of the Involvement Attributes could be to find out whether or not the management of the Involvement Attributes improve rehabilitation outcomes. A *nul* hypothesis for this could be

> "The management of the Involvement Attributes by people in rehabilitation and the rehabilitation staff do not improve rehabilitation outcomes."

This could be associated with how the Involvement Attributes are related to self-efficacy, as discussed in chapter eleven (Study Discussion).
.

Qualitative Research that Develops Further Understanding.

Relationships

In further study, the relationships that older people have with the staff and the staff have between themselves needs to be considered if environments are to be made conducive to increasing involvement in rehabilitation through the relationships older people encounter. Research questions include:

> "What is the nature of the relationships between staff and people in rehabilitation?"
>
> "How might a person-centred care environment affect involvement in rehabilitation?"
>
> "How much does team cohesion affect involvement in rehabilitation?"
>
> "How sophisticated/relevant/useful/detrimental/individual and service user orientated, are the views of the staff and people in rehabilitation?"

The Decision-making Process

The decision-making process in rehabilitation seems to be pivotal to risk management and rehabilitation progress. Using the Theory of Involvement If decisions are left to the staff and this affects the Involvement Attribute set the staff's decision-making approach will effect reduced involvement. If decisions are made without the collaboration of staff, then the older person might be at risk of creating an imbalance within the Involvement Attributes operating without sufficient information and skill or when physically unfit to progress. Currently, there seems to be a dearth of mechanisms designed to assess the ways patients make decisions in rehabilitation. This might be answered by asking

> "What mechanisms do people in rehabilitation use to make decisions in rehabilitation after acute illness?"
>
> "What is the relationship between decision-making and the Involvement Attribute set?"

Learning

Since the Involvement Attributes operate within relationships, both the older people and the staff need to learn. Examples of learning of the older person and staff include how their impairments can best be managed through the management of a robust Involvement Attribute set. Research into how older people and staff learn in their rehabilitation would be useful in the determination of the best learning strategies. This might be answered through questions such as

> What is the meaning of learning in rehabilitation?
>
> How does the learning of the staff differ from that of the people in rehabilitation?
>
> How can learning become a joint enterprise between staff and people in rehabilitation?

Conclusion to the Thesis

The reduction of the state in the welfare of UK citizens requires that individuals, and in the case of rehabilitation their families, take more responsibility for themselves within the health care system. The wide ranging reaction of the public to health responsibility, described in chapter two, Background, from being more passive to being more active, means that for some this will be a difficult change period, whilst for others this will provide opportunities to gain more from health care interventions. The policy-driven changes provide the opportunity for the creation of a health care environment which requires the staff to recognise, accept and act to move away from the traditional paternalistic style of management of people in health care towards collaboration and partnership. Similarly, to become more involved, people in rehabilitation relying on health care staff too much, have to exchange their position as a passive receiver of health care, for this same collaborative partnership relationship.

These developments are not without their difficulties, requiring that patients demand their rights and take up the concomitant responsibilities and staff facilitate this within the therapeutic relationship. One of the difficulties in altering the traditional paternalistic position of the staff is the control of the environment that health care professionals possess. Examples of this, in this current research, are staff control of admission to the Intermediate Care unit (Appendix One) and the vocal and behavioural gestures that people in rehabilitation are required to learn in order to collaborate. The importance of this in health care was discussed throughout the thesis, especially in chapters two (Background), three (Literature Review), Four (Theoretical Framework and Method) and twelve (Relationships).

The Theory of Involvement constructed in this thesis increases clarity in the understanding of the involvement of older people in their rehabilitation after acute illness. The theory explains involvement in terms of a set of Involvement Attributes that are divided into two groups. Involvement in rehabilitation is maximised when the Involvement attributes are strong, balanced and the two groups, psychological and action-based are aligned. Involvement in rehabilitation occurs within relationships between all the stakeholders in the rehabilitation events. It is therefore suggested that the therapeutic relationships will be served well within a person-centred care framework (McCormack, 2003, McCance et al., 2011). Within therapeutic relationships the major stakeholders both determine and are determined by each other during rehabilitation. The meaning of involvement for older people in their rehabilitation after acute illness is therefore

> "A joint commitment within therapeutic relationships to determine and be determined in the pursuit of an Involvement Attribute set that is strong, balanced and aligned".

The inspiration of this current research was my inability to become involved sufficiently in the care and rehabilitation of my parents when they became frail. *A posteriori*, it is clear to me that involvement in rehabilitation is a complex construct associated with the way staff and older people approach each other in the context of the health care environment and actions promoting involvement flounder because of a lack of clarity and understanding. This current research provides opportunity to counter this but changes will be difficult. It is not enough to demand that staff move away from paternalistic, towards collaborative and partnership, relationships. It is not enough to facilitate involvement through legislation and directives to set up environments that might favour involvement, for example, the Local Involvement networks (LINks). Involvement concerns all the stakeholders, including the staff and patients, in a joint enterprise.

This current research can be considered to be a call to action to change the *status quo* and develop health care relationships, where older people and staff work and learn together in rehabilitation.

Appendices

Appendix One: Extracts from the Intermediate Care unit Service Directory

Material, in the service directory that is not relevant to the thesis has been removed. Clarification phrases have been [bracketed]

WORKING IN PARTNERSHIP

[Name of Organisation]

SERVICE DIRECTORY

INTERMEDIATE CARE

Introduction

Intermediate Care Services bridge the gap between hospital and home by providing varied levels of rehabilitation to support older people whilst recovering from trauma, injury or created by lifebreakdown of a current situation.

Therapeutic interventions and individual assessments form the basis for a structured care plan to maximise function and independence.

The NHS Plan (July 2000) set targets focused upon partnerships between Secondary, Primary and Social Care. The emphasis was to: -

- Prevent Inappropriate Admissions to Hospital
- Prevent inappropriate admission to permanent care
- Responding to avert a crisis
- Maximise the recovery potential for people recovering from trauma and illness
- Promote independence, quality of life and the potential to continue living in the community
- Promote a timely discharge from hospital

The Intermediate Care unit

A 25 bedded unit, the purpose of which is to provide holistic, goal orientated rehabilitation to patients failing at home (step up) and post acute patients (step down) aiming at best achievable function and maximal attainable physical, psychological, social function and independence.

The aim of the unit is to provide continuous assessment of needs from admission through to transfer of needs from admission through to transfer of care in partnership with patients, carers and the multi-disciplinary team, so that early diagnosis is used to facilitate rehabilitation programmes and decisions regarding future care needs are made at a time when the acute phase of illness has subsided.

The patient should be deemed medically stable (however, in some cases this may mean that the patient is still unwell, needing continuation of treatment e.g. antibiotic therapy, medication review) on referral to the unit.

For the purpose of the unit, medical stability is defined as

- Unlikely to require an acute medical intervention or diagnostic investigation at time of referral
- Care facilitation criteria is for a skilled nursing unit (Complex and frequent interventions by nurses are acceptable, provided that they do not prevent rehabilitation.)
- Patient is deemed as having the potential for rehabilitation and recovery within 6 weeks.

The patient's mix of rehabilitation, medical, nursing and therapy needs cannot be met elsewhere in the intermediate care service.

In the event of a patient requiring nursing/residential long term care, transfer to an interim bed may be necessary.

The Intermediate Care Service is:

- Targeted at people who would otherwise face unnecessarily prolonged hospital stays to acute in-patient care or long-term residential care.

- Provided on a basis of a comprehensive assessment, resulting in a structured individual care plan that involves active therapy, treatment or opportunity for recovery.

- Have a planned outcome of maximising independence and typically enabling patients/users to resume living at home

- Are time limited - normally no longer than 6 weeks and involve cross professional working with: -

  A single assessment framework

  - Single professional records

  - Shared protocol

  What we are not: –

  - Inpatient recuperation

  - Forms of transitional care that does not involve active therapy or interventions to maximise independence i.e. ready to leave acute care but waiting for longer term care packages.

  - Longer term rehabilitation or support services

There should always be a planned end point for intermediate care. Any patient requiring extensions beyond six weeks should be exceptional and authorised by a senior clinician

OVERALL CRITERIA [for admission to the Intermediate Care unit]

- Resident of [Name of geographical area]
- Over 65 (referrals for people under 65 will be considered)
- Medically stable, not requiring immediate medical treatment
- In agreement to participate in care programme
- Assessed by relevant professionals to determine their needs and outcomes associated to their agreed destination

EXCLUSION CRITERIA

- Acutely ill patients
- Medically unstable patients
- Patients for whom the diagnostic and investigative phase of their medical management is materially incomplete
- Patients whose primary needs would be more appropriately met by the mental health service
- Patients with disruptive, challenging behaviour or who wander (patients would be unable to participate in a rehabilitation programme)
- Patients who require respite care

Appendix Two: An Extract from a Conversation Transcript

In this extract from a recorded conversation the bold type is a nurse support worker and the non-bold type is Participant Four

Participant 4.Period 2. 44 Conv

You know what we spoke about yesterday, there was a man going to record you. I'll just get you out of bed ready for breakfast. You are going to get recorded. Is that alright with you? OK? We are going to be tape recorded alright?

I am just going to do the normal you know when we get you up out of bed alright pet. OK. Have you had a good sleep then?

Aha great yes.

I'll just switch that [radio] off a minute, I'll just switch it off alright? cos they're just coming round to do the breakfast.

Have you got any pyjamas on?

No.

Well I'll tell you what I'll do. I'll just go and get your pyjama bottoms. No, I'll just put ours on for the time being, right.

Alright I've got a pair of our pyjama bottoms, alright.

Shut them curtains.

Ok. Alright pet.

Excellent. It was warm mind wasn't it last night?

Warm?

Aha. I think some of the patients were red hot the night staff had to open the windows.

Appendix Three: Confirmation of Wellness (letter) to Take Part in the Research

Date

Dear Dr (name)

Medical Agreement for a patient to take part in a research project

Following our recent discussions and my distribution of the research information sheet about my doctoral research project I write to ask if you consider your patient --- to be medically stable and well enough to take part in the research. Please contact me if you have any further questions on ward 23 or on the telephone number below.

If you consider the patient to be well enough to take part in the research I would be grateful if you complete the form below and return it to me at the address on the form.

Research project

The Older Person/Practitioner Partnership: Involvement of the Older Person in their Rehabilitation Care.

I agree that my patient (name) is medically stable and well enough to take part in the above research.

Signature

Print name

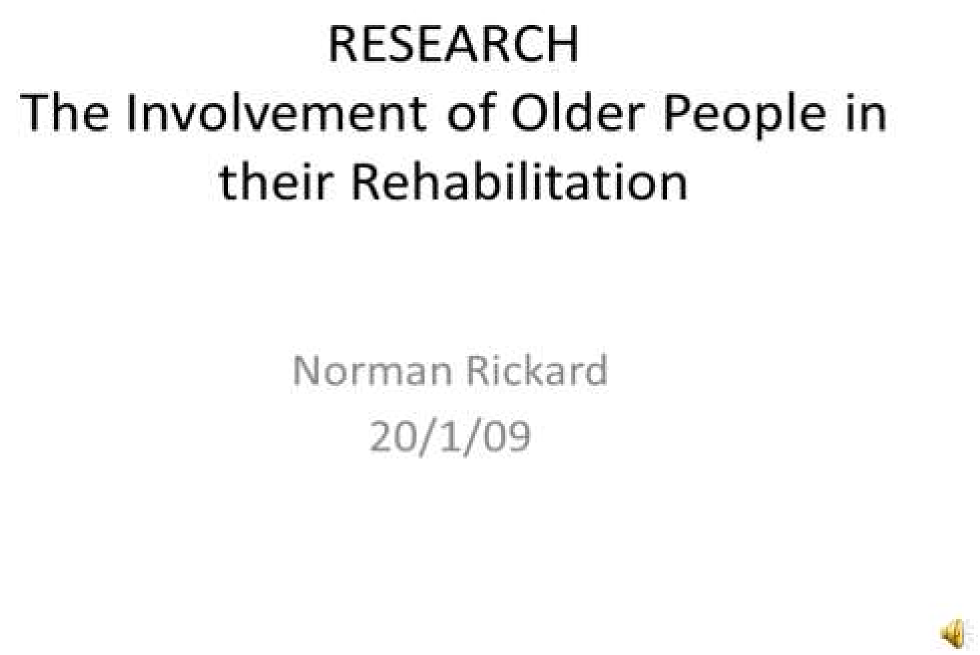
Please return this form to;
Norman Rickard, Room H05 Research Centre, Coach Lane Campus East
University of Northumbria, Coach Lane, Benton, NE7 7XA

Tel

Yours Sincerely

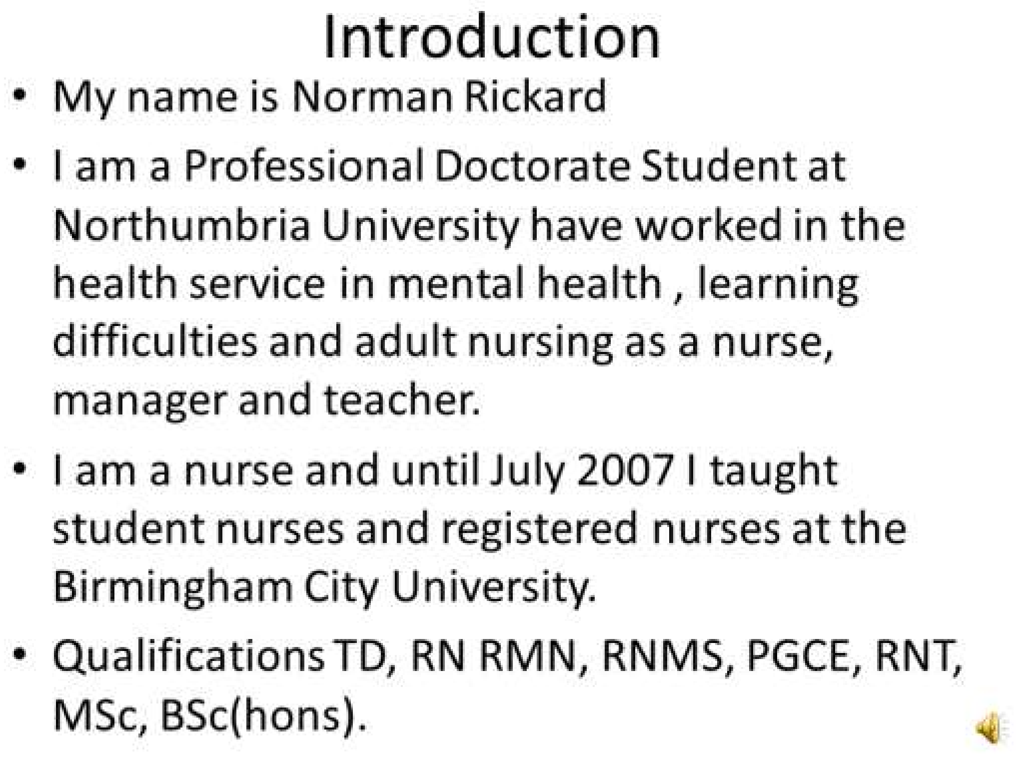
Norman Rickard, Post Graduate Student, Northumbria University

Appendix Four: Power Point Presentation to Staff



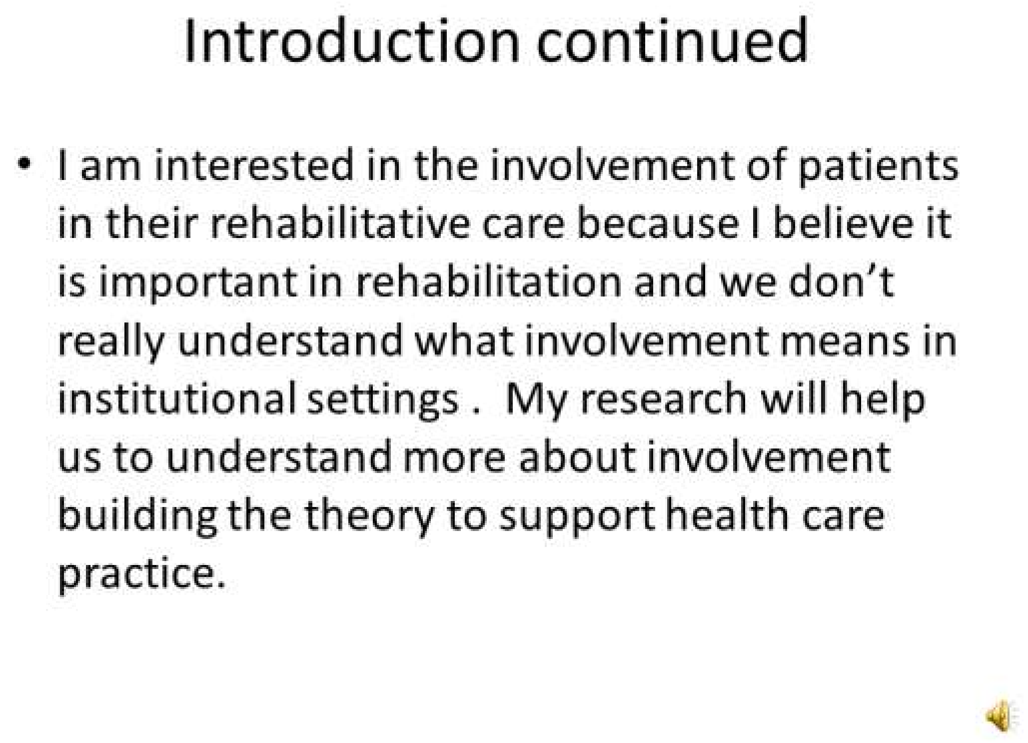
RESEARCH
The Involvement of Older People in their Rehabilitation

Norman Rickard
20/1/09



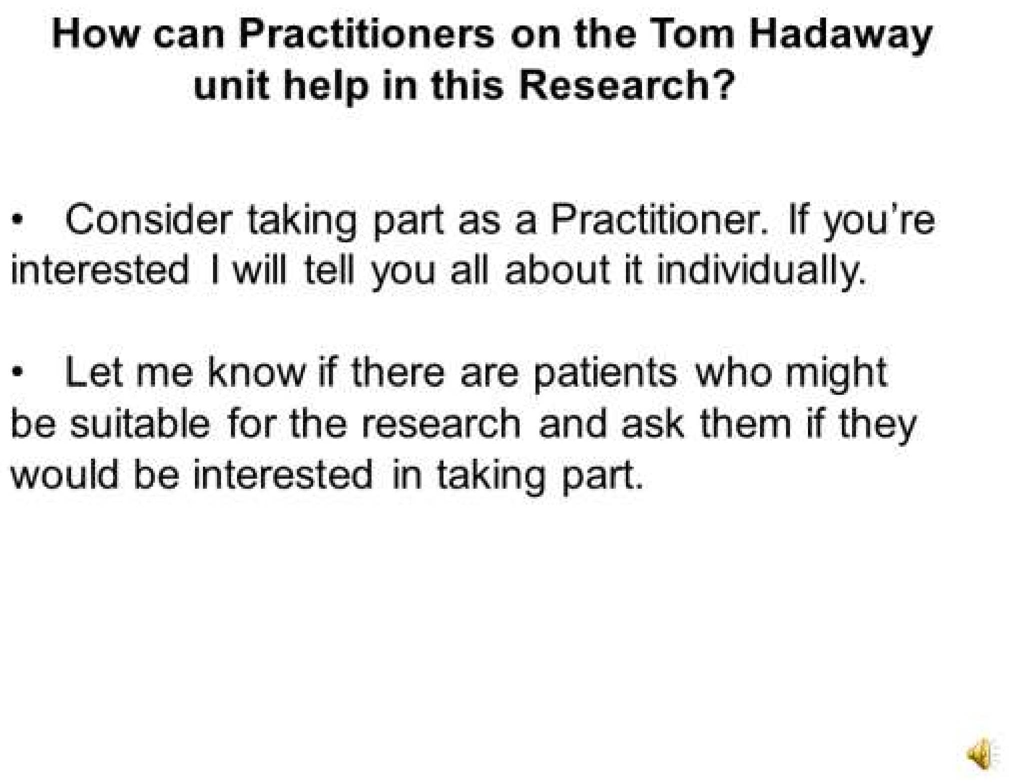
Introduction

- My name is Norman Rickard
- I am a Professional Doctorate Student at Northumbria University have worked in the health service in mental health , learning difficulties and adult nursing as a nurse, manager and teacher.
- I am a nurse and until July 2007 I taught student nurses and registered nurses at the Birmingham City University.
- Qualifications TD, RN RMN, RNMS, PGCE, RNT, MSc, BSc(hons).



Introduction continued

- I am interested in the involvement of patients in their rehabilitative care because I believe it is important in rehabilitation and we don't really understand what involvement means in institutional settings . My research will help us to understand more about involvement building the theory to support health care practice.



How can Practitioners on the Tom Hadaway unit help in this Research?

- Consider taking part as a Practitioner. If you're interested I will tell you all about it individually.
- Let me know if there are patients who might be suitable for the research and ask them if they would be interested in taking part.

Which patients would be suitable?

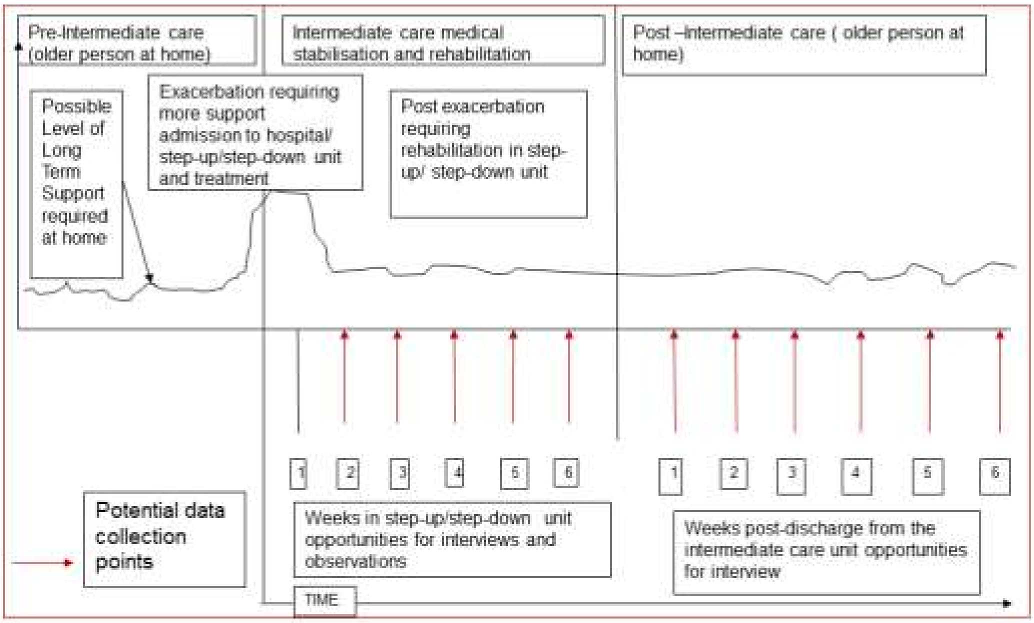
- All patients over 65 who would be able to give informed consent to take part in the study.
- Those who will require at least four weeks stay in the Tom Hadaway unit
- AND

- are physically well enough to take part
  you think they would be able to take part
  there are practitioners for the patient who wish to take part
  the patient can understand the documents without the need for a translator.

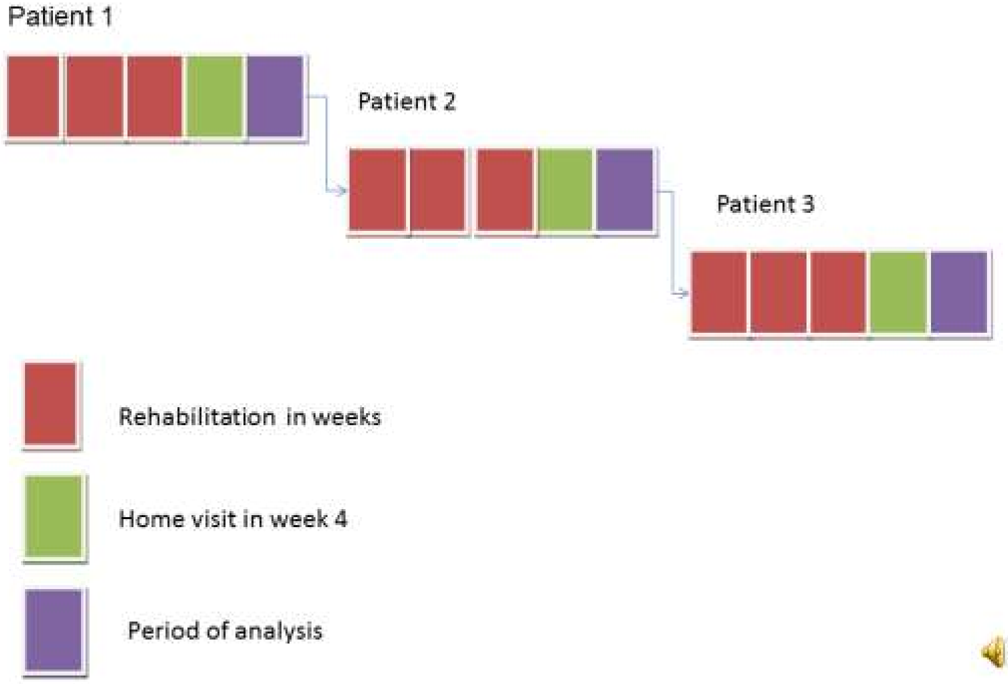
What can I give you? (Apart from a smile)

I'm not sure but If you are studying for something I might be able to help in some way. (Please let me know if I can help.

Involvement of the older person in their rehabilitation



Data Collection on the Tom Hadaway Unit



Informal observation of the work of the unit and selection of cases for longitudinal study	Sampling based on analysis of Case 1	Sampling based on analysis of Cases 1 &2
1st Patient Interviews	**2nd Patient** Interviews	**3rd Patient** Interviews
Interviews with Practitioner (3) about 1st patient	*Interviews with Practitioner (3) about 2nd patient*	*Interviews with Practitioner (3) about 3rd patient*
Observations (3) of discussion with 1st patient and Practitioner	*Observations (3) of discussion with 2nd patient and practitioner*	*Observations (3) of discussion with 3rd patient and practitioner*
Analysis 1	*Analysis 2*	*Analysis 3*

Appendix Five: Extract from the Narrative of Participant Three

Quotes are marked using the interview number and the line number so 30, 14-25 would be interview 30 lines 14-25. This means that the lower the number of interview the earlier the interview was carried out in the rehabilitation stay. Numbers in a red font cross-link to the open codes taken from the interview transcriptions. Memos are also written in red font.

Background

Gordon is a man in his early 80's who had many driving jobs in his life including heavy goods vehicles and retired as a taxi driver at the age of 76. Gordon liked this job and told me he knew when he couldn't catch fare dodgers and he would just let them go (33, 35) 352. Gordon lives alone in a rented bungalow and has a small West Highland Terrier (32, 416-419) 350 as a companion (32, 430-432) 350. Gordon's daughter, Sandra, is his main carer, backed by his son-in-law who tends the garden (30, 188-189), 315 makes sure Gordon is safe in the shower (36, 370-387) 315 in case "I fall or owt" (36, 387) 315 attending Gordon at other times in the absence of Sandra for example putting Gordon to bed when he returned from the social club (35, 48?). Sandra is able to be Gordon's main carer because she lives

> "At the other end of the street" (30,58) 303 and is able to

"pop in when she comes home from work" (30, 60-62) 303 and phones him (30,60-62) 303

Sandra has an unusual work schedule as she works in a supermarket garage from 5am until 9am (32, 275-280) 349.

Prior to Gordon's admission to the Intermediate Care unit Sandra worked hard for her father shopping (32, 287-290) 303 paying bills (32, 297-300) 303 doing the housework (32, 322-325) 303 (36, 510-522) 310 washing him (30, 140-142) 310 making sure he had everything he needed (32 302-305) 310 and that he was safe. Sandra also helped Gordon move around the bungalow.

> "If I want to walk anywhere for when I walk to the passage or the toilet she used to help me" (30, 246-248) 303

She also cleaned him after the toilet (30, 299-300) 303, 323

Sandra "cooked, washed, she'd do everything" (32, 179) 303

Sandra also bought food for Gordon and left it for him when she wasn't there during the day.

Gordon used to make "stuff" for himself during the day provided by Sandra (32, 370-374) 347

In addition Sandra took Gordon to the social club (on Sundays) (32, 253) picked him up and took him home (32, 255-257) 303 (35, 487) 303,319

Memo 301
Sandra compensates for her father's lack of internal resource

A typical day (what used to happen before he lost the use of his legs and came into the Intermediate Care unit)

Gordon would get up in the morning on his own (35, 32) he would get himself washed (35, 62) at the sink (35, 71). Gordon made his own full English breakfast (35, 38-52)/ makes his own breakfast sometimes (35,393)/ Sandra would make Gordon breakfast if he hadn't had it before she arrived (35,401) 362

When Sandra arrived to see Gordon in the morning (around 930 am) she would get him ready (35, 36) and then Gordon would sit down in the chair (35, 84) and play with the dog (35, 23) 362

Sometimes Sandra would come in and make Gordon's lunch (35, 92) 362

Sandra would come to see her father at 4pm (35, 88) and make tea (35,389) 362

Gordon would go to bed around 1030pm (35, 405) 362

Gordon tends to sit alone in the kitchen and has varying opinions of this

There was some motivation to do something

"Well it's... you get bored sitting in one place all the time" (30, 199) 316.

Conversely Gordon told me

> "I have a nice garden and I have a nice chair to sit in and I keep just looking outside all the time but I don't mind. It's quite good" (30, 201-204) 317.

Memo 302
To me, this indicates that Gordon might be quite happy to sit in his chair **reliant on the external resources of his daughter** and not really benefit from the external resources that were about to be given to him to rehabilitate him in the Intermediate Care unit.

Problems and compensation mechanisms

Gordon's medical and functional problems started with a stroke four years ago which ended his career as a driver and left Gordon with a left arm weakness which causes some functional problems in terms of washing and dressing. Even so, after the stroke, Gordon managed to go outside to the shops and to his social club using a mobile scooter and walk round the garden at his bungalow. Late last year (2009) Gordon started to have blackouts and was admitted to hospital. After his return to the bungalow Gordon became frightened to leave his chair unless someone else, usually Sandra, was with him in case of falls (36, 387). He passed the time of day doing nothing (30, 97) 306. This reluctance to mobilise lead to a reduction in his ability to walk, transfer from chair to commode, get into bed and go to the bathroom. Consequently the carer role for Sandra increased and she moved into the bungalow with her father. The precipitating reason for Gordon's admission to the Intermediate Care unit was he "Literally just went off his legs that is his muscle strength decreased" (31, 26) 327 and Sandra became exhausted with the extra work.

Memo 303
The **reduction in Gordon's internal resources was too much** for the family to cope with. Gordon came into the Intermediate Care unit to have some extra external resources that instead of just helping him would help him to help himself and so increase his internal resources.

Medical treatment

During the stay in the Intermediate Care unit Gordon's Parkinson's disease was assessed and treated and the pain he had in his legs (36,544) 368, which may have been caused by him using them again (32, 83-105) 343, was reassessed when Gordon uncharacteristically asked for pain killers "...Just when I'm in bed I would fancy some painkillers, you know, to get me to sleep" (36, 570-571) 369 at the end of period three. This was treated by the provision of a new prescription (36, 546) 368.

The difference between the Intermediate Care unit and home Gordon changes his mind as he progresses through the unit

At the beginning of period 1 in the Intermediate Care unit Gordon found it difficult to decide which was better for him the unit or his home. He said, I

"Can't really say" the difference (30, 225) 319,

"It's more or less the same" (30, 227) 319

"There's nothing bad about it" (the unit) (30,228-229) 319.

Nothing has surprised Gordon about the unit (30, 230-233) 319

"It's all just as much as expected" (30, 234-235) 319

The reason given for this lack of surprise was:

> "Erm, cos I'm more or less lived on my own all the time" (30, 239) 319

When asked if life could be made better in the unit Gordon said

> "I don't think so" (30, 237) 319

Whilst Gordon was talking to a practitioner who asked if

“going home would be a hard struggle? or do you... it’s just going back the way it was”

Gordon replied

> “Just the same” (32, 171-174) 319

Memo 304
This fits in with the assessing physiotherapist who went out to Gordon’s home and who thought that Gordon. The incentive for rehabilitation appears weak.

> “didn’t seem that bothered that he was going into care” (38, 202) 377

Later in the same week (period 1) Gordon seemed to change his mind

“oh I’d like to stop at home” (32,521) 319

Because I’ve always been on my own “ (32,525) 319

Even so at the end of period one (around one week) Gordon saw little difference between home and the unit

> “Well it’s more or less the same because I just sit on my own at home” (33,502) 319

Memo 305
Gordon doesn’t seem to have a goal oriented approach to rehabilitation but is led by others. He does not seem to be on a pathway towards rehabilitation. However, in period 2 Gordon seemed to change his mind he seems to have developed an incentive to rehabilitation but this turned out to be weak and not associated with rehabilitation.

Appendix Six: Letter of Ethical Approval from the National Research Ethics Service

NHS

National Patient Safety Agency

National Research Ethics Service

County Durham & Tees Valley 2 Research Ethics Committee
Professorial Unit of Surgery
University Hospital of North Tees
Piperknowle Road
Stockton-on-Tees
TS19 8PE

Telephone: 01642 624164
Facsimile: 01642 624164

05 November 2008

Mr Norman AS Rickard
Post Graduate Student
Northumbria University
Room H05 Coach lane Campus (East)
Northumbria University
Coach Lane, Benton Newcastle upon Tyne
NE7 7XA

Dear Mr Rickard

Full title of study:	**The Older Person/Practitioner Partnership: Involvement of the Older Person in their Rehabilitation Care**
REC reference number:	**08/H0908/78**

Thank you for your letter of 01 November 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
GP/Consultant Information Sheets	1	09 June 2008
Letter of invitation to participant	3	04 August 2008
Protocol	4	05 November 2008
Application	5.6	05 September 2008
Letter of invitation to participant	Practitioner V3	04 August 2008
Guidance to assessing general understanding and capacity	1	01 September 2008
Interview Schedules/Topic Guides	1	28 June 2008
Response to Request for Further Information		01 November 2008
Participant Consent Form: Patient	4	29 October 2008
Participant Consent Form: Practitioner	4	29 October 2008
Participant Information Sheet: Patient	4	29 October 2008
Participant Information Sheet: Practitioner	4	29 October 2008

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/H0908/78	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

R Duncan
Chair
Email: leigh.pollard@nhs.net
Enclosures: "After ethical review – guidance for researchers

Appendix Seven: Guidance to the Assessment of General Understanding and Capacity

Guidance To Assessing General Understanding and Capacity

- This should be done prior to signing the consent form.
- The person must be able to hear the statements and questions.
- Check that the person has read the information leaflet.
- Identify that they can ask questions at any time.

‘I know that you have read the information leaflet, but one of the things we need to check is that people understand the study and what it will involve for them if they choose to take part. So if I can read you a small section of the information leaflet and then check your understanding of it. Is that all right?

Q1.

“We are asking you to take part in a research study to investigate the health and needs of older people and find out why some people stay healthy and independent whilst others are not doing so well. If you take part I would ask you questions about your life and to carry out some medical tests with you.” (explain tests)

‘Are you happy to do this?’

- **Yes**……go to Q2.
- **No**……..‘Is there anything I can explain that might make you willing to take part, or any questions I can answer?’ If refusal is adamant: end interview. If explanations can be given (without compulsion) and the person agrees to take part, proceed to Q2.

Q2.

‘So, in a few words, can you tell me what the study is about?’

- If answer implies or includes: Investigate health of older people to find out why some people stay healthy and independent whilst others are not doing so well. Go to Q3.

- If answer is muddled or confused on <u>first ‘pass’</u>, return to Q1.

If answer is muddled or confused on <u>second ‘pass’</u>, return to Q1.
If answer is muddled or confused on <u>third ‘pass’</u>, discuss with relative/main carer to decide if the interview should continue. Given that the person at this stage has said “yes” (Q1), if the relative/carer and interviewer feel it appropriate to continue, and presuming there is no resistance to continuing, a decision could be made at this stage that the person seems to be

consenting to their level of understanding and the relative/main carer could then be asked for proxy assent. The rest of the questions below could still be asked to check further understanding or any overt objections.

Q3.

'From what I said earlier, can you tell me what would happen to you if you agreed to take part in this study?'

- If answer implies or includes: An interview or questionnaire and medical test go to **.

- If answer is incorrect go to **Q4.**

Q4.

'Just to remind you, I said we would need to ask you questions about your life. Are you still happy to take part in the study?'

- **Yes**……go to Q5.
- **No**……..'Is there anything I can explain that might make you willing to take part, or any questions I can answer?' If refusal is adamant: end interview. If explanations can be given (without compulsion) and the person agrees to take part, proceed to Q5.

Q5. **'So, can you tell me what would happen to you if you agreed to take part in this study?'**

- If answer implies or includes: An interview or questionnaire and medical test go to **.
- If answer is muddled or confused on <u>first 'pass'</u>, return to Q4.

If answer is muddled or confused on <u>second 'pass'</u>, return to Q4.

- If answer is muddled or confused on <u>third 'pass'</u>, discuss with relative/main carer to decide if the interview should continue. Given that the person at this stage has said "yes" (Q1), if the relative/carer and interviewer feel it appropriate to continue, and presuming there is no resistance to continuing, a decision could be made at this stage that the person seems to be consenting to their level of understanding and the relative/main carer could then be asked for proxy assent. The rest of the questions below could still be asked to check further understanding or any overt objections.

**The interviewer should continue to check that the participant is willing to take part throughout all of the interviews, checking that he or she is comfortable and offering to pause or stop if the person seems distressed. The reason and description of all tests should be explained again before completion. No test should be taken unless the person agrees freely for example after explaining about the blood sample the person freely offers his or her arm.

Appendix Eight: Invitation to Take Part in the Research (Older Person)

Logo

Date

Invitation to take part in research (Older person)

Dear

Now that you have indicated to the clinical staff that you might be interested in participating in some research I would like to introduce myself. My name is Norman Rickard. I am studying for a research degree. I am interested in how patients are involved in their care within rehabilitation care. I would like to invite you to take part in a research study. You have been invited to take part in the study because you have been admitted to an intermediate care ward. Attached to this invitation letter is an information sheet that tells you what the research is about and how you could contribute.

Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the information sheet carefully. Talk to others about the study if you wish. Later there will be time for you to ask me about anything about the research that is not clear to you. I will also be able to provide you with more information about the research if you need it.

(Please turn over)

Take time to decide whether or not you wish to take part.
I will be pleased to discuss the research whenever you like.
My contact details are on the bottom of this letter and the information sheet. I will be in touch with you soon.

Best wishes

Norman Rickard
Post Graduate Student Tel:

Appendix Nine: Study Description (Older Person)

Patient Information Sheet

Please read whilst I am with you so that I can answer your questions.

Study Title

Involvement of the older person in their rehabilitation care.

What is the purpose of the study?

To find out how patients are involved in their care and what this means to them and their carers. By doing this work I will be able to build up a picture of what involvement in care means to the various people which may help to improve care.

Why have I been asked to take part in this study?

You have been invited to take part in this research study because you have been admitted to an intermediate care ward and need temporary help to get you back to independence.

Do I have to take part in the study?

It is up to you to decide. I will describe the study and discuss this information sheet with you. I will then give you the information sheet. Later, if you agree to take part, I will ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. Withdrawal will not affect the standard of care you receive.

What am I being asked to do?

You will be asked to take part in 4 interviews in total. 3 will be in the hospital whilst you are an in-patient and one after you leave. Each interview will last about 40 minutes. The interviews will be about how involved you are in your care and what difference you think this makes. I will also observe discussions with you and your carers.

Where will the interviews take place?

The interviews will take place whilst you are in the unit and at your own home, or elsewhere if you prefer, once you have been discharged. The interviews are not part of your normal care. You may wish to have a friend or relative with you during any of the interviews.

Are there any disadvantages of taking part?

I cannot think of any disadvantages but you need to be aware that the four interviews will take up about three hours of your time. I will be happy to discuss any concerns that you have with you.

What are the benefits of taking part?

This study is unlikely to help you directly but the information I get from this study may help improve the treatment and care of future patients in intermediate care in North Tyneside.

Confidentiality.

Collecting the data.

The data for this research, our discussions, will be collected by tape recorder as we speak. I will give you a demonstration of this if you wish. On the tape recorder you will be given a unique identifying number which will be linked to your name on one piece of paper only. This will be kept in a locked cupboard in the university. This means you will not be able to be identified from the tape. Once the interview is over the tapes will be listened to and the interview will be typed out.

Storage of the interview tapes and papers

The tapes will be kept safe in a locked cupboard in the university until after the research is complete. At that time the interviews and discussions will be wiped from the tape. The paper versions of the interview will be kept by me, again in a locked cupboard in the university. No record of your name or any other personal details will be kept on the tape or paper versions of the research data. The interviews and discussions will be kept anonymous. Few people will have access to the tapes and the papers. These will be myself, my supervisors who are training me and regulatory authorities who may want to monitor the quality of the research. The interview information will only be used in connection with this research study.

What will happen to the results of the research study?

The results will form part of my doctoral thesis which will be completed by the end of 2010. The results will be published in health care journals in an anonymous form. They will also be made available in the university library and a summary of the results will be sent to you at home. Finally this study may be presented at conferences and relevant community groups. You will never be identified in any publication, at a conference or community group without your consent though I would like to be able use some of your words exactly as you said them.

Use of your words exactly as you said them

I may like to use some of the things you say to me as direct quotes in my research thesis, papers and presentations. If you do not agree to this when I show them to you after the research analysis, I will not use them. If you do agree I will make sure that you will not be able to be identified from any of these quotes.

Who is organising and funding the research?

The research is organised by the University of Northumbria in conjunction with [Name of research setting organisation]. It is funded by me through university fees. No-one is being paid to do the research.

Who has reviewed the study?

The research was initially reviewed by my supervisors at the University of Northumbria and then the university ethics committee. In addition to this all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee who protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by a local Research Ethics Committee.

Where can I find further information about the research?
Further information and contact details

1) For further information about this research please contact me,[Researcher Name and Telephone Number]
2) If you are unhappy about the study please contact: [Supervisor Name and Telephone Number]

What will happen if I want to withdraw from the study?

If you wish to withdraw from the study, all you need to do is tell me. My contact details are given at the bottom of this page. If you wish I will destroy all the interview material collected before your withdrawal or you may wish to let me keep it. In either case your name and details will be kept confidential.

Observation periods

If for any reason you wish that the researcher to leave during any of the observation periods then he will withdraw from the room.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to me. I will do my best to answer your questions on 07931784046. If you remain unhappy you may wish to contact [Name and telephone number] the Manager in charge of the Intermediate Care unit.

Harm

It is highly unlikely that you will come to any harm because of this research. During an interview or in a period of observation if you do not wish the interview/observation to carry on for whatever reason, the interview/observation will be stopped. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against the Primary Care Trust. You may have to pay your legal costs.

What will happen if unsafe practices are observed during interviews or observations?

If unsafe practices are observed during interviews or observations then the researcher will abide by the code of conduct issued by the Nursing and Midwifery Council and discuss the issue with the practitioner involved. If necessary the issue will be reported to the line manager.

The results of the research

The results of the research will be written up as part of my doctoral thesis and will be presented to community groups interested in involvement of patients in their care. A summary of the results of the research will be sent to you at home. At no time will anyone be able to identify you from the thesis, presentations and summaries.

(Please Turn Over)

Contact points

[Name and telephone number of the researcher, Intermediate Care unit manager and Research Supervisor]

Appendix Ten: Consent Form (Older person)

identification number for this research:

Consent Form (participant) (Page One of Two)

Title of research project

Involvement of the older Person in their Rehabilitation Care
Please initial

	Yes	*No*
I confirm that I have read and understand the information sheet dated 29/10/08 (version four) for the above study.	☐	☐
I have had the chance to ask questions about the study and these have been answered to my satisfaction.	☐	☐
I am willing to be interviewed	☐	☐
I am willing to be observed in meetings with My practitioner.	☐	☐
I am happy for my comments to be recorded.	☐	☐
I give permission to allow my words, said during the interviews and observations, to be used as direct quotes in research reports provided I have the option to review this permission when shown the quotes that may be used.	☐	☐

Please Turn Over...

Consent form (participant) (Page Two of Two)

I understand that I can withdraw at any time if I change my mind and this will not affect my care in any way. ☐ ☐

I have been assured that my name and details will be kept confidential and will not appear in any printed documents. ☐ ☐

I ……………………………………(name of participant)

understand the information presented to me by

………………………….. (name of researcher) and agree to

take part in the research.

Signature …………………………(Participant) Date: ……………

Signature ………………………... (Researcher) Date: ……………

Researcher contact details:
[name and telephone Number of the researcher]

When completed one for patient, one for researcher site file and one for medical notes

Appendix Eleven: Research Questions, Devised Prior to the Research and Presented to Research Ethics Committees

Introduction

Period One

Initially both health care professionals and the patient will be assessing the situation to see what can be done, forming their own views together and separately. They are unlikely to know the extent of possible rehabilitation.

Period Two

As the patient and practitioner begins to understand his/her personal strengths and weaknesses so discussions might begin as to what is possible for the patient led by the patients' abilities and the resources of the multidisciplinary team.

Period Three

As the end of the rehabilitative period draws closer, preparation for returning to an assisted independence will be made. Practitioners are likely to pull away from care delivery leaving the patient to do more on their own.

Indicative Questions

To enhance clarity and for the sake of brevity when referring to patients in the questions below, the term "Mrs" is used as an example and infers all titles.

Indicative questions to Older People in Period One

Tell me what happened to bring you into this place.
Did you have any health care needs before you came into this place?(closed). What sort of help did you have before you became unwell this time?
What are the most important things in your life now?
What sort of help do you hope to gain from this rehabilitation unit?
Has anything happened in hospital that surprised you?
What do you understand by being involved with your care?
Have you any experience of being involved in your care previously?
In what way are you involved in your care now?
Would you like to be more involved? (closed) In what way would you like to be more involved in your care?
What would help you become more involved?
If you were more involved in your care what would you like to happen?
How do you think you could contribute to this?

Indicative Questions to Staff in Period One

What are your general aims when caring for patients in intermediate care?
What are your specific aims for Mrs ...
How does the system you work in help you/hinder you to fulfil your aims?
What individual improvements in the care of Mrs .... would you like to happen?
Has anything happened that has surprised you?
In what ways is Mrs...... involved in her care (examples required)?
Do you think her level of involvement is optimal? (Closed) If no: How do you think the involvement of Mrs .... could be improved?
What difference does the involvement of Mrs .... make in her care?
How do you think you could contribute to improving involvement?
Are there any other non-professionals who you take advice about Mrs..... from?
What difference do these make in the care that you offer Mrs Smith?

Indicative Questions to Older People in Period Two

What are the most important things in your life now?
Are you able to do more things for yourself than last week? What can you now do?
Do you feel the staff understand your needs? (Closed) How do you know this?
Last time you told me that...What are the differences since last time I talked to you?
What do you want to get out of being in hospital at this time?
Has anything happened that surprised you?
How involved do you feel in your care at this time?
Would you like to be even more involved? (closed) In what way would you like to be further involved in your care?
What stops you being more involved?
What would help you become more involved?
What difference do you think more involvement might make to your progress?
What improvements in your care would you like to happen?
How do you think you could contribute to this?

Indicative Questions to Staff in Period Two

Have your aims changed for Mrs ...? (closed) In what way have your aims changed?
How is the system working to help you/hinder you to fulfil your aims?
What improvements in the care of Mrs .... would you like to happen?
Has anything happened to Mrs .... that has surprised you?
In what ways is Mrs...... involved in her care (examples required)?

Do you think her level of involvement is optimal? (Closed) If no: How do you think the involvement of Mrs .... could be improved?
What difference would the involvement of Mrs ..... make in her care?
How do you think you could contribute to improving her involvement?
Are there any other non-professionals who you take advice about Mrs..... from?
What difference do these make in the care that you offer Mrs Smith?

Indicative Questions to Older People in Period Three
What is happening in your care now?
Are you able to do more things for yourself than last week(closed) What can you now do?
Do you feel you are making progress? (closed) What progress are you making?
Do you feel you are preparing for leaving unit?
How are you involved with your care at this time?
Last time you told me that.... What are the differences are since last time I talked to you?
Has anything happened that surprised you?
Would you like to be even more involved? (closed) In what way would you like to be further involved in your care?
What stops you being more involved?
What would help you become more involved?
Now that you are nearly ready for home what difference do you think more involvement might make to your progress?
What improvements in your care would you like to happen?
How do you think you could contribute to this?

Indicative Questions to Staff in Period Three
Have your aims changed for Mrs ...? (closed) In what way have your aims changed?
How is the system working to help you/hinder you to fulfil your aims?
Has anything happened that has surprised you?
What improvements in the care of Mrs .... would you like to happen?
In what ways is Mrs...... involved in her care (examples required)?
Do you think her level of involvement is optimal? (Closed) If no:How do you think the involvement of Mrs .... could be improved?
What difference would the involvement of Mrs ..... make in her care?
How do you think you could contribute to improving her involvement?
Are there any other non-professionals from whom you take advice about Mrs.....?
What difference do these make in the care that you offer Mrs Smith?

Indicative Questions to Older People in Period Four (at home)

Have you felt that the stay in the unit has helped you?
What sort of things did you benefit from being in the unit?
Has anything happened to you that you were surprised at?
Now that you are home how involved were you with your care?
Would you have liked to be even more involved? (closed)
In what way would you have liked to be more involved in your care?
Is there anything that stopped you being more involved?
How could staff help you become more involved if you were ever admitted to a rehabilitation bed again?
What difference do you think more involvement might make?
What improvements in your care do you think more involvement would make?
How do you think you could contribute to this?
Do you think things would have been different if you had been encouraged to be more involved?

Indicative Questions to Staff in Period Four

What were your general aims when caring for Mrs....?
How did your aims match your achievements for Mrs....
How did the system you work in help you/hinder you to fulfil your aims?
What improvements in the care of Mrs .... would you have liked to happen?
Has anything happened that has surprised you?
In what ways was Mrs...... involved in her care (examples required)?
What difference did the involvement of Mrs ..... make in her care?
How do you think the involvement of Mrs .... could be improved?
How do you think you could contribute to improving involvement?
Are there any other non-professionals who you took advice from about Mrs....?
What difference did these make in the care that you offered Mrs ....?

Appendix Twelve: Question Development Set For Participant Four

Indicative Questions to Participant Four in Period One

Tell me how you came to be here?

Did you have any health care needs before you came into this place? (closed)

What sort of help did you have before you became unwell this time?

What information were you given about the rehabilitation unit before you came in?

Which assessments have been done with you?

Who has set goals with you?

What goals did you set?

How do you like being cared for/treated in the rehabilitation unit?

What are the most important things in your life now?

What sort of help do you hope to gain from this rehabilitation unit?

What do you like most about how you are cared for?

What is the least good about being in here?

Has anything happened in the unit that has surprised you?

What is your main aim now?

Has there been anything here that has seemed out of place

- not quite right?
- Unhelpful?
- Embarrassed you?
- Offended you?

Do you feel staff understand your needs? How do you know this?

How much of your personal care do you do on your own?

How much personal care could you do on your own?

How much of your personal care do you want to do on your own?

Tell how you would like to be if you had no restrictions?

What decisions do you make about your rehabilitation?

In what ways do you participate in your care now?

Would you like to be more involved? (closed) In what way would you like to be more involved in your care?

Why is being involved important/ not important?

Could your life in the unit be made better?

How do you think you could contribute to this?

Indicative questions to Patient 4 in Period 2

What's happening in your physiotherapy?

Have you done any more physiotherapy since I saw you on Wednesday

How many times have you been to physiotherapy?

Would you like to do more to help yourself? (Closed)

Do you have any questions about your physiotherapy? What risks are you taking whilst you are here?

What do you talk about when the physiotherapists are wheeling you to the physiotherapy room?

How did you get on with the occupational therapist ?

Do you think she understood your needs?

What equipment do you think you will need at home?

Have you tried the standing exercises she mentioned?

How much of a risk do you think your home rugs pose for you or your wife?

Do you think you will need care call?

Tell me about your energy levels. What are you doing about them?

Do you think you are improving?

What do you think are the biggest risks for you at the moment

Do you get good explanations from the staff about what they are doing? What's good about it?

How interested about the progress are you?

What do you want to be able to walk for?

How much do you want to be able to walk?

How far do you need to be able to walk?

Where do you think the motivation for you to get better comes form?

Tell me about the other parts of your care for example medication

Is there anything/anyone spurring you on to do more?

How much do you feel you need to ask permission to do things?

Is there anything you would like to do extra?

How much do you feel you have to remind the people of your needs?

Do the staff understand your needs? What would help me to understand how much they understand your needs?

How much does pain or anything else affect your life at the moment?

How do you let the staff know you're in pain/ anything else? How do you know they listen?

Where do you get your ideas about what to expect from?

Do you talk to your wife about it? Does she give you ideas?

Is there anything that you could do for yourself that you are not doing?

What might help you do more for yourself?

How much do you feel you are a priority for the physiotherapists?

How many of your expectations are met?

Does anyone (Drs nurses carers physios) discuss your future here?

Do they listen to you about the things you want?

How much power do you have to direct your care? Is there any areas that you don't understand?

What would you like to change if you had the chance?

How do you discuss with the staff about the things you want to happen?

What sort of things do you do that help you keep abreast of the care that is delivered/ plans for the future?

Are you able to weigh up the pros and cons about your future health care? What enables you to do that?

What sort of involvement do you have about your care?

What would help me understand the level of involvement in the decisions made about your future health care?

How do you feel about staff making the decisions that you might make yourself?

How much do you feel at home here?

How much do you think you can do to help the staff?

Does anything get in the way of your progress?

Why is being involved important/ not important?

How do you think you could contribute to this?

Could your life in the unit be made better?

What advice would you give to someone who was coming into this unit?

Is there anything else you would like to tell me about your involvement in your care?

Patient 4 in Period 3

What are the differences are there since last time I talked to you?

Do you feel you are making progress? (closed) What progress are you making?

What can you do now walking wise?

How does this match up with the aims you started with and where you want to be?

How has this transition been made?

Who is responsible for that transition?

Have you done any new physiotherapy?

How did you get the new regime?

What do you need to be able to do that you cannot do at the moment?

How will you get back to that?

Have you asked about your discharge?

Has anything happened that surprised you?

What decisions do you make about your care now?

What do you think involvement your re-enablement is?

Are your relatives involved in anyway?

Would you like to be more involved? (closed) In what way would you like to be more involved in your care?

Why is being involved important/ not important?

In what ways could you participate more in your care?

Could your life in the unit be made better?

How do you think you could contribute to this?

Do you feel the staff understand your needs? (Closed) How do you know this?

What concerns have got about going home?

Tell me about your physiotherapy experiences

How much physiotherapy have you had each day?

Would you have liked a different amount?

How could you have got that different amount do you think?

How much extra physiotherapy are you doing off your own bat?

Do you think you could improve a bit more?

Do you think you could need some extra physiotherapy?

What can you do now that you couldn’t do when you came in?

    Washing

    Dressing

Are these something you might strive for? Why? Why not?

What will stop you going downhill again?

Whose responsibility is it to stop you going downhill?

What's the most important thing in your life now?

If someone were coming in here for physiotherapy and asked you for advice what might you say

Indicative questions to patient 4 in period Four (at home)

How long were you in the rehabilitation unit?

Have you felt that the stay in the unit has helped you? (closed How has your stay helped you?

What was your goal in hospital?

Are you pleased with the overall outcomes of your stay in the rehabilitation unit?

What was the best about your stay?

What was the worst thing about your stay?

What sort of things did you benefit from being in the unit?

Has anything happened to you that you were surprised at?

Who was the person that influenced you most at the hospital? Why was this?

What did you personally add to your rehabilitation?

What was your level of involvement in your rehabilitation?

Would you have liked to be even more involved? (closed)

In what way would you have liked to be more involved in your care?

How could you have been more involved in your rehabilitation?

What say did you have about when you were discharged?

What were the things that freed you up to be discharged?

Did you feel you were discharged at the right time?

What sort of signs let you know it was time to be discharged?

What would help me to understand the level of control you had over your care in the rehabilitation unit?

Did you ever think that you could have altered your stay in any way by finding ways to let the staff know more of what you wanted?

Did you enjoy being looked after in hospital?

Is there anything that stopped you being more involved?

What would have helped you be even more involved in your care?

What difference do you think involvement makes?

What difference do you think more involvement might make?

What improvements in your care do you think more involvement would ake?

How do you think you could contribute to these improvements?

What risks are there now for you in the nursing home?

How were these discussed with you at hospital?

How has being on ward 23 affected you as a person?

Is there anything else you would like to tell me?

Appendix Thirteen: Open Codes from Particiapant Four, Jack

These *in vivo* codes are based around jacks Goals. Goals became a category later in the analysis. The coding scheme is the same as that described in chapter Four Theoretical Framework and Method

From the participant in Period One

> "To get completely independent walking showering and looking after myself" (40, 206-207).
>
> "I was able to walk outdoors with just a walking stick" (40, 213-214).
>
> "…I want to, as I said, get back to being independent at home so that I can see my family and friends and do a little bit of moving around… I'd like to be able to get out and about" (40, 325-329).
>
> "To get back to as near as normal as I possibly can" (40, 481-482).

From the Participant in Period Two

> "…And to be able to do my own thing like going in the shower room and having a shower and getting dressed and just make progress" (43, 462-468).

From the Participant in Period Three

> "Oh, I think getting home and getting myself mobile so that I don't become a burden. I don't want to become a burden. I have no ambition to be in an old peoples'home playing bingo and singing Hallelujah. Just to get back to normal" (46, 602-606).

(From the physiotherapist Period One)

> "About midweek of the first week [name] was walking with a Zimmer Frame but he didn't want to go home like that he wanted to go home with a stick" (41, 54-57).

From the Occupational Therapist Period Three

> "He does have a stick at home which he quite likes to use and he is hoping to get back to that" (47, 13-15).
>
> "He is aware he's not as good as when he had his stroke. He feels he recovered quicker after that, but he is still hoping, I think, for some improvement" (47, 15-17).

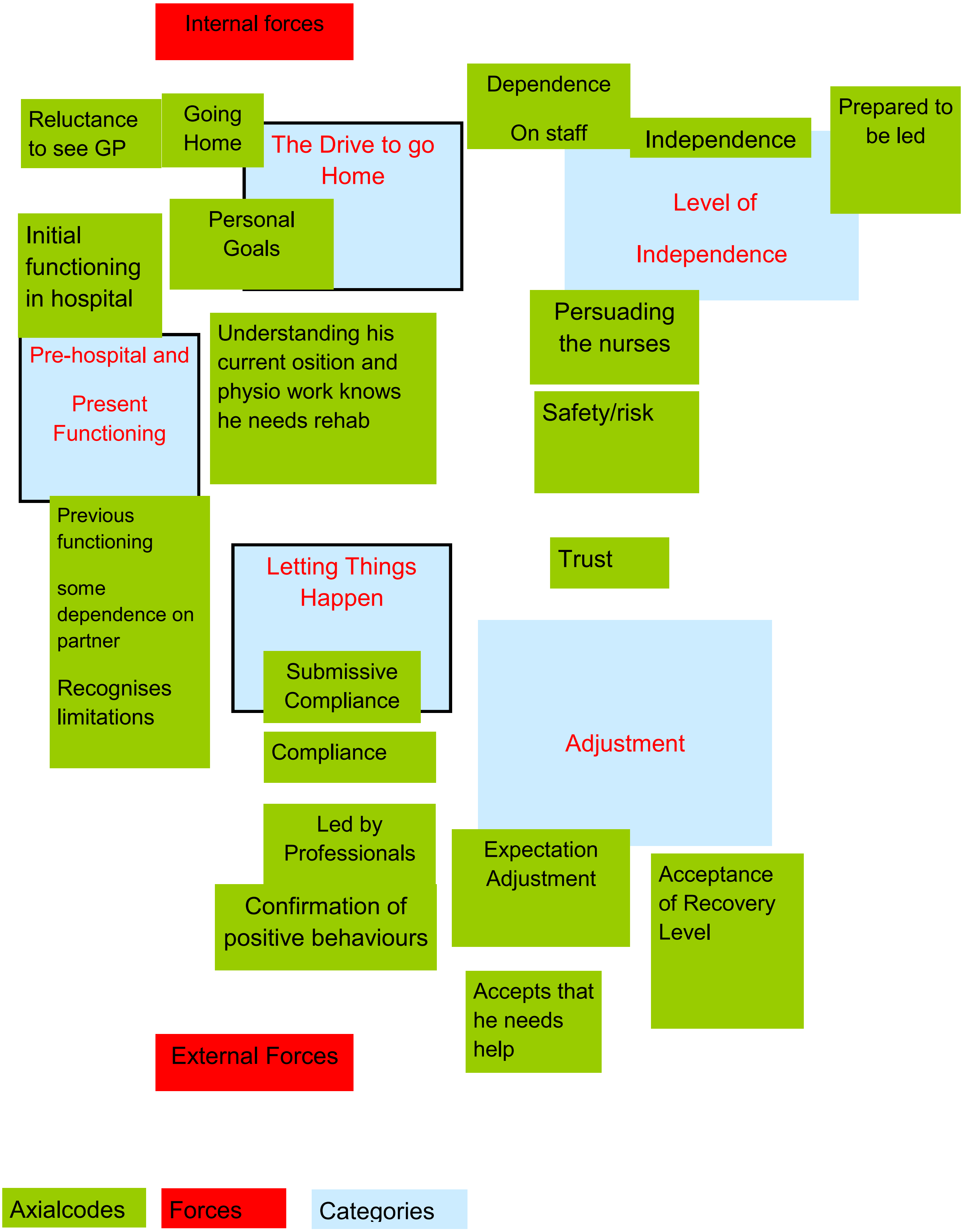
> "He can stand out of his chair now" (47, 19-20)

(From a conversation with the Occupational Therapist Period One)

When discussing his future with the occupational therapist jack made it clear that he was going to go home.

> "Well, that's the main aim so I can get out and about" (42, 521).

Appendix Fourteen: Axial Codes for Participant One: Joe



Appendix Fifteen Examples of Diagrams used in the Development of the Constructions

Participant One, Joe

At home	In the Intermediate Care unit	At home after Discharge
Looked after partner	Desparately wants to go home Does what he is told	Looked after by partner
	Physiotherapists happy to lead	Confused about his position

Partcipant Two, Josie

At home	In the Intermediate Care unit	After Discharge
Heart failure Lymphoedema Needs carers	Deciding whether to go home or into care. Refuses to let family help An organiser, socially competent Moody at times	Bedfast Still organising Despair
	No physiotherapy input	

Appendix Sixteen: Cross-Case Comparison

Y=Yes N=No. Numbers equate to the Line Numbers in Each of the Participant Narratives.

Common Category	Participant 1	Participant 2	Participant 3	Participant 4
Accepts the status quo	N 57-60	N 101-103 N 108-109	N 135-136 N 129-133 N 118-119 N 138 N 276	N 71-76 N 84-89
A personal incentive to improve	Y 463, Y 596-598	N515-525	N 19-33 N 58-63 N 97-112 N 115 N 122 Y 327-328 N 656-662	Y 62-63 Y 489-491
The development of a personal vision of a future orientated pathway				
Future orientation	N785-794 Y890-891	Y100-104 N275-278 N280-281 N284 N286-290 Y311-340		Y151-156 Y 353 Y358-359 Y643
Development of personal aims related to rehabilitation or personal pathway	N 626-646 Y67-70	Y358-362	N129-133	Y71-76 Y84-88 Y644-648
Personal goals within the pathway	Y67-68	Y157	Y232 Y236-239 Y242-246 Y273 Y276	Y163 Y176-178 Y195-197 Y237 N 435-438

Continued…

Common Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
Physiotherapy/ practitioner led goals within the pathway	Y 274 Y 362-371 Y 386-387 Y 437-438 Y 460-461 Y 494-524 Y 639-647	N 411-412 N 420-431 N 475-477	Y 156-158 Y 227-228 Y 259-261 Y 268-271 Y 343-344 N 583-586	Y 499-501
Instigation of developments	N 383, N 391-399	Y 436-447 N 450-452 Y 454-455	N 478-486	Y 287-289 Y 364-377
Personal organisation of self	N 421-422, N 430-434 Y 425-428	Y 625-630 Y 692-696		Y 364-377
Personal organisation of the available resources	Y 568-574, Y 627-631	Y 615-618		Y 223-234 Y 364-368
Responsibility for the pathway				
A level of personal responsibility for the Decisions/goals	N 99-101 N 274 N 362-371, N 460-461 N 900-904	N 127-130 N 133-134 N 137-138 N 147-148 N 159-163	N 467-474 N 564-571 N 668-684 Y 494-501	Y499-501 Y192-193 Y243-247 N449-446
Personal responsibility beyond the pathway	N 375-376 N 467-469	Y 970-1001 Y 777-781	Y 394-400 N 742-770 N 785-790 N 800-805 Y 837-840 N 842-854 Y 857-858 N 861-862 N 869-873 N 878-880	Y 525-527 Y 542-557
Personal drive wants to do better	Y 306-308, N 544-551 N 859-863 Y 958-959	Y 597-608		Y 112-118 Y 144-147 Y 387-397 Y 663-674

Continued…

Common Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
The will to progress, enthusiasm works hard	Y 58-59 Y134-136 Y152 Y183-188 Y 261-267 Y 269-270 Y 530-537 N 636-646 N 677-686 Y 702-705 N 780-782 Y 865-884 Y 888-889 Y 311-340	N 244-251 N 254 N 257-260 Y 292-293 Y 293-296 Y 311-340	N 294-298 N 564-571 Y 572-573	Y 176-178 Y 259-261 Y 387-397 Y 453-457 Y 663-674
Outstrips physio-therapy resources				Y 463-473
Process divergence from staff, dissonance	Y 198-232 Y 337-349 Y 409-414 N 472-474 Y 465-469 Y 939-942		Y 432-433 N 467-474	
The production of goals beyond the pathway which use appropriate resources	N 373-377 Y 956-959			Y 542-545 Y 546-557
Physiotherapy or team goals beyond the pathway	Y 523-524		Y340-341	Y 703-705
Cognitive reduction of dependency over time	N 978-979			Y 364-377

Continued…

Common Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
Decision-making				
Has the capacity to make decisions	Y 378	Y 767-768	Y 220-222	
Makes self-determining personal choices	N 140-143 N 170, N 386	Y 777-781 Y 881-896	N 425-427	Y 364-377 N 439-440
Purposeful risk taking				N 406-413 N 419-421 N 439-446 Y 577-579 Y 595-596 Y 592-594
Use of resources **Work in collaboration with staff**				
Discusses issues with staff	Y 757-773			
Asks for appropriate help	N 113-117 N 161-164, N 690-698	Y 657-670 Y 672-679 Y 706-707 Y 739-743 Y 839-852 Y 1056-1058	N489-493	Y192-193 Y 568-571
Makes suggestions	Y 293-295	Y 709-704		Y 287-289 Y 293-294
Not overwhelmed by the care function (Y=overwhelmed)	Y 455-458 N 293-295 N 306-308	Y 352-353	Y 619-624 Y 629-643 Y 649-655	Y 323-326 N 364-377
Absorbs practitioner direction into a personal pathway	N 183-184	Y 701-702		Y 515-520

Continued…

Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
Use of resources **Work in collaboration with staff (continued)**				
Dependent on practitioner direction	Y 134-135 Y 140-143 Y 161-164 Y 167-168 Y 170 Y 183-184 Y 261-267	Y 515-526 Y 534-539 Y 542-546 Y 553-560 Y 564-566 Y 745-746 Y 771-774 Y 794-796		Y 132-134 Y 165-167 Y 499-501
Negotiates		Y 709-714 Y 717-722		
Subsidence of embarrassment	Y 442-445 Y 455-458	Y 870-871		Y 329-330
Partnership				Y 293-294
Relates ADLs to rehabilitation				Y 195-197 Y 509-510 Y566-567
Trusts that the resources available will help and are managed virtuously	Y 167-168 Y 277, Y 494-504, Y 513-524		Y 528-530 Y 538-539	Y 297-298 Y 306-311
Hope that things will get better		Y 100-104 Y 108-109 Y 115-119 Y 140-144 Y 158		Y 358-359

Continued…

Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
Good use of available physical resources				
Acceptance of system failures and tries to circumvent problematic issues/potential issues	Y 316-330	Y 631-650		Y 475-482 Y 609-628
Understands how resources might be better used	Y 293-295	Y 632-634		Y 364-377 Y 703-705
Programmes extra exercises into the day when other resources fail	N 604-613	Y 436-447 N 448-452 Y 454-455	N 579-580	Y 223-234 Y 243-247
Use of family resources in rehabilitation		N 216-223 Y 226-230	Y 19-23 Y 75-80 Y 173-175 N 176-177 Y 191-193 Y 364-365 Y 372-373 Y 707-710 Y 732-733 Y 752-757	Y 678-701
Use of family resources in organisation	Y 425-428 N 430-433	Y 625-630 Y 652-654 Y 777		Y 364-367

Continued…

Category	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
Learning				
Takes opportunities to gather new information	Y 254-259	Y 550-552 Y 739-743 Y 747-752		Y 119-126 Y 306-311 Y 323-326
Adapts learning to personal situation	Y 238-250, Y 417-418			Y 499-508 Y 515-520 Y 592-602 Y 630-642
Carries out a useful self-appraisal	Y 409-414, Y 579-584 Y 483-491		Y 456	Y 110-111 Y 259-264 Y 383-389 Y 403-405 Y 515-520 Y 560-567 Y 630-642
Poor self-appraisal		Y 924-925 Y 941-947 Y 1045-1047	Y 198-200 Y 203-205 Y 286-290	
Recognises limitations		Y 927-929	Y 250-256	N 579-580 Y 603-607 Y 597-602 Y 650-656

Appendix Seventeen: Out of the Blue Ideas

Compensatory Resource Mechanisms

Rehabilitation can be seen as a compensatory resource mechanism. Within this rehabilitation can be seen as the increase of internal resources, during the employment of external resources, for example, the physiotherapist's time and walking frames, to reduce the effect of functional impairments which, together, facilitate increased independence.

Rehabilitation is the increase of internal resources, and the employment of external resources, to reduce impairments and the effects of impairments facilitating increased independence.

There is sometimes a goal divergence between the patient and practitioner at the end of the rehabilitation period.

Participants have staged goals requiring hope belief and trust

Direction is more appropriate (needed) when the participant starts rehabilitation as the patient may be weak and not understand his limitations, the best way forward, or the best use of the external resources.

The relationship with practitioners should develop into a partnership but this does not always occur.

- The difficulties of the organisational imperatives curtailed rehabilitation,
- the desire of the patient to go home
- the reaching of a safe position to go home

Involvement is concerned with learning and the demonstration of the adaption of that learning to practical issues as independence increases

Just because some older people rely on the staff for direction it does not mean that this status quo has to remain. There must be techniques to help people to see that they have to take charge of their own pathway.

Using the definitions found there are three different but interlinked cases where there was some form of involvement and one case where the involvement was very low. The negative case was not the one that went into care but one that went home

Being involved is not a binary function and has many different facets

For example, all participants have to have some trust in the system, but how this trust is manifested is different. Joe and Gordon have a blind trust. Jack has a trust in the rehabilitation system as a resource. Josie's trust is a source of friendship.

Reliance

All the participants were reliant on the staff and all developed an attitude of reduced embarrassment for personal care. They felt they had to do this and yet this is the antithesis of personal responsibility for these medically stable patients.

Reliance has many interpretations reliant reliance on others for outcomes (do what your told Gordon and Joe), Reliance on others to play their part and reliance on others to have your interests at heart (Jack and Josie)

Personal responsibility

All the patients influenced their rehabilitation pathway through the way they interacted with the practitioners. Two took a stronger personal responsibility (Josie and Jack whilst Gordon was the weakest. Jack's personal responsibility took the form of incorporating the practitioner advice into his pathway and exercising and eating extra to build up stamina. Gordon did what he was told. Joe also did what he was told but, as he moved through the pathway, reacted against poor timings of physiotherapy sessions. Josie asked for advice and built her own vision of what life would be like outside the Intermediate Care unit but this was based on false hopes.

Participants all wanted to leave but Gordon this was not linked to a personal will to improve and for Josie it was linked to a will to start a different life.

3 of the patients were clear about the power arrangements but this was managed differently:

Josie tried to build up friendships, Gordon did not seem to care what happened to him, Joe and Jack were aware that the staff had the key to resources and the timing of discharge.

One of the patients took opportunities of self-appraisal and personal learning

Two of the patients left many decisions that could have been taken by them, to the staff.

Staff

Some of the staff work in care mode too much and liaison with physiotherapist and occupational therapists were weak.

Patients become overwhelmed by care and just let care staff do what they want to do.

When considering the consumerist versus the democratic view (Lupton 1998) it is sometimes hard to separate the two as, for example, the consumerist view of user involvement can be disguised as a democratic view. An example of this is where patients have rights for example the patients' charter, the patients have rights but not of redress and do not to discuss how the service is managed on their behalf.

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