Some(body) else: Transitions in embodiment after stroke

by

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Abstract

**Background and purpose.** The body in stroke physiotherapy is everywhere in practice but neglected as a concept in clinical theory. This study explored the embodied experience for people with stroke at the time of transition from rehabilitation to community living. The purpose of this study was to gain an in-depth understanding of embodiment to inform the delivery of physiotherapy after stroke.

**Subjects and methods.** Seven people with stroke, aged 66 to 89 years, were interviewed one month after discharge from a stroke rehabilitation unit. Interviews were analyzed using grounded theory methodology.

**Results.** Two main themes in the embodied experience of stroke were: (1) a ‘divergent body-self’ where participants referred to an objective physical body, separate to oneself; and (2) a ‘cohesive body-self’ reflecting a sense that ‘it’s all me’. A ‘divergent body-self’ included subthemes of a body that was ‘strange’, ‘unpredictable’ and ‘effortful’. In contrast the ‘cohesive body-self included subthemes of ‘freedom’, ‘control’, and ‘identity’, reflecting experiences of bodily movement and personal independence. Participants fluxed between these perspectives, within moments and over time, with these perspectives influenced by ‘anchors’ that included their environment, knowledge and attitudes.

**Discussion and conclusion.** The bodily experience of stroke is dynamic and intimately connected with a person’s sense of self. The social and physical environment as well as individual attributes can serve to ‘anchor’ people within their embodied experience of stroke. Physiotherapists play a pivotal role in how stroke survivors view themselves and their body following stroke. Physiotherapy practice could be enhanced by theory that acknowledges the
integral connection between body and self. This study supports the need to widen the scope of rehabilitation for stroke health care professionals, including physiotherapists.
Conference presentations arising from this thesis;


Publications in submission from this thesis;

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Thank you also to the Canterbury District Health Board who supported me financially with my studies, and my colleagues who assisted with recruitment as well as expressing reassuring interest throughout.

A generous thank you to my participants who kindly gave me not just their time but were overwhelmingly honest.

Finally I’d like to acknowledge my husband; my rock.
Table of Contents

Abstract ........................................................................................................................................... ii
Acknowledgments ................................................................................................................................. v
Table of Contents ................................................................................................................................. vi
List of Tables .......................................................................................................................................... x
List of Figures .......................................................................................................................................... xi

Chapter 1: Introduction ......................................................................................................................... 1
  1.1 Background ...................................................................................................................................... 1
  1.2 Research aim .................................................................................................................................... 3
  1.3 Definition of key terms ................................................................................................................... 4
  1.4 Thesis structure ............................................................................................................................ 5

Chapter 2: Background ............................................................................................................................. 7
  2.1 Introduction ...................................................................................................................................... 7
    2.1.1 Researcher perspective ........................................................................................................... 10
  2.2 Embodiment .................................................................................................................................... 13
    2.2.1 Embodiment in stroke .......................................................................................................... 18
      Self-body split .............................................................................................................................. 21
      Altered bodily awareness .............................................................................................................. 23
      Altered perception of self ............................................................................................................. 24
      Social context in embodiment ..................................................................................................... 26
      Dynamic self-body relationship .................................................................................................. 26
    2.2.2 Embodiment in chronic illness ............................................................................................... 28
    2.2.3 Embodiment and physiotherapy ............................................................................................. 31
  2.3 Stroke overview ............................................................................................................................... 35
    2.3.1 Stroke pathology .................................................................................................................... 35
    2.3.2 Epidemiology .......................................................................................................................... 36
    2.3.3 Stroke rehabilitation in New Zealand ..................................................................................... 37
    2.3.4 Overview of Christchurch stroke services ............................................................................. 38
    2.3.5 Biculturism and embodiment ................................................................................................. 39
Chapter 4: Embodied Experience

4.1 Sense of self

4.1.1 An Altered Body

Objectification

Unreal

4.3.2 An Unpredictable Body

Being careful

Tiredness

4.3.3 An Effortful Body

Struggle to move

Concentration

4.4 Cohesive body-self

4.4.1 Control

Bodily control

Control over life

4.4.2 Freedom

4.4.3 Self-identity

Altered body impacting on identity

Enduring identity in spite of changed body

Enhanced identity

4.5 Anchors

4.5.1 Knowledge

Learning

Understanding physiological changes

4.5.2 Attitude

Personal outlook

Higher purpose

Effect of fear

4.5.3 Environment

Social

Physical

Rehabilitation

4.6 Summary of the embodied experience

Chapter 5: Discussion

5.1 Introduction

viii
5.2 The body and sense of self as intertwined ................................................. 122
5.3 Divergence in body and sense of self .................................................... 123
5.4 Cohesive body and self ....................................................................... 126
5.5 Influencing the embodied experience .................................................. 132
  5.5.1 Importance of context .................................................................... 133
  5.5.2 What helps? Anchors .................................................................... 134
5.6 The embodied experience as central to stroke physiotherapy .............. 139
  5.6.1 Embodiment and current physiotherapy approaches ...................... 140
  5.6.2 A different approach? Implications for practice ......................... 146
5.7 Limitations ......................................................................................... 151
5.8 Recommendations for future research ............................................... 153

Chapter 6: Conclusion .............................................................................. 156

Glossary ................................................................................................. 158
References ............................................................................................... 163
Appendix 1 ............................................................................................... 173
Appendix 2 ............................................................................................... 174
Appendix 3 ............................................................................................... 178
Appendix 4 ............................................................................................... 179
Appendix 5 ............................................................................................... 181
Appendix 6 ............................................................................................... 182
Appendix 7 ............................................................................................... 184
Appendix 8 ............................................................................................... 186
List of Tables

Table 1: Summary of key articles which consider the embodied experience of stroke survivors as a primary aim.................................................................p.19

Table 2: Oxfordshire Community Stroke Project classification for ischaemic stroke....... p.60

Table 3: Overview of participants.................................................................p.71
List of Figures

**Figure 1:** Application of Grounded Theory in this study. p.54

**Figure 2:** Theoretical representation of the embodied experience for stroke survivors transitioning from hospital. p.74
Chapter 1: Introduction

The body is central to all physiotherapy practice and to a degree there is an assumed understanding of what the body means to physiotherapists. This assumption extends to person-centred practice being viewed as synonymous to adopting an all-encompassing view of the body. The study reported on in this thesis critically evaluates the concept of the body in physiotherapy practice by exploring the embodied experience of stroke reported by people after leaving hospital.

1.1 Background

It is through our bodies that we know and experience the world around us. My body is me. This is not something that I have ever really questioned until recently. In my role as physiotherapist I have worked with people’s bodies every day. Despite the physical focus of my work, I have always considered myself as a ‘people person’, enjoying getting to know people as individuals, and I felt this reflected in my practice. I considered that I treated people as a ‘whole’. However, in recent years, I have become aware that rather than being ‘holistic’ my physiotherapy work in stroke rehabilitation is enshrouded in dichotomies. ‘Can’ versus ‘cannot’; ‘before stroke’ versus ‘after stroke’; and from my patients perspective, ‘me’ versus ‘my body’. I started wondering, what does it mean for someone to have a body which cannot allow them to be that ‘active person’ they had always identified as?
For many stroke survivors their bodies are abruptly changed by stroke, and their future is clouded with uncertainty. In my role as community physiotherapist, I met people after leaving hospital following stroke. While in hospital there appeared to be a preoccupation with getting home. However, once home, people seemed to question what it meant for them to have had a stroke and how this translated into their own life story. I became increasingly attentive to the way patients described who they were and their bodies. What did it mean for someone to consistently refer to their arm as ‘lame Larry’? Had they always seen their arm as lame and separate to them self, and how did my approach as a physiotherapist influence their experience of living with a changed body? Essentially, I began to question what the embodied experience of stroke was, as the comments of patients indicated embodiment went beyond the physical body of muscles and joints that is so central to physiotherapy.

For me, embodiment meant how I use my body as a vehicle to interact with the environment around me. At times I have loved the sensations my body provides, such as when running and biking, and felt gratitude for the freedom it allowed. At other times I have felt self-conscious and critical of how I appeared and this impacted on my self-esteem and consequent interactions with others. This was my experience of a ‘normal’ body but what would a post-stroke body feel like? In my physiotherapy role and through previous postgraduate studies I had read extensive literature around the general experiences of stroke survivors including their transition home. From this literature and my own observations I knew that people sometimes felt frustrated with their bodies and uncomfortable about their appearance, although I had often seen the uniqueness of each
stroke survivor’s experience. I had attempted to acknowledge and respect patients’ feelings as they experienced these emotions but, until undertaking this research I had never considered what the changed relationship between their physical body and other aspects of their embodied self may mean for them in the wider context of their existence. This left me with preconceptions about approaches to physiotherapy in stroke that influenced my own clinical practice but also many questions about the focus of my work.

I started to read more specifically about the embodied experience of stroke and found that, although this is a topic being increasingly considered, embodiment is not yet reflected in rehabilitation theoretical models. Instead what I found was confusion around terminology, contradictions between professions, and a lack of clarity. If this is what the evidence reflects, I wondered what was actually happening in healthcare practice. In my experience of physiotherapy, the body still seemed to be considered as some kind of machine to physiotherapists. In particular, I started to question our understanding of the embodied experience of stroke when people leave hospital. I wanted to understand this better so that our practice could be improved and consequently started my research journey.

1.2 Research aim

The purpose of this study was to explore the embodied experience of stroke for people over the age of 65, one month after hospital-based rehabilitation.
1.3 Definition of key terms

‘Embodiment’ can be defined as “how we live in and experience the world through our bodies” (Merleau-Ponty, 1962 as cited by Wilde, 1999, p.27). Embodiment theory acknowledges that the lived body is never just a material object in the world, but the basis for understanding others, self-reflection and participating in everyday life (Charmaz, 1995). The embodied experience recognizes the innate connection between the body, self, others and the world (Kitzmüller, Häggström, & Asplund, 2013). There are multiple interpretations of embodiment for different professions and areas of health, and this will be revisited in Chapter Two.

A ‘stroke’, also known as a cerebrovascular accident, is the rapid loss of brain function due to disturbance of blood supply to the brain. A stroke can either be ischaemic whereby the brain is deprived of blood through a blockage or haemorrhagic when there is a bleed from the vessels into brain tissue. The resultant cell death in the brain causes a range of neurological impairments depending on the location and extent of brain tissue damage.

‘Physiotherapy’ aims to provide services that develop, maintain and restore people’s maximum movement and functional ability through the application of physical modalities (World Confederation for Physical Therapy, 2014). Functional movement is quoted as being central to what it means to be healthy, and practice is thought to include assessment and treatment aimed at enhancing functional movement (Higgs, 2001; Wikström-Grotell & Eriksson, 2012; World Confederation for Physical Therapy, 2014).
‘Rehabilitation’ is “a proactive, person-centred and goal-oriented process” which aims to “improve function and/or prevent deterioration of function, and to bring about the highest level of independence physically, psychologically, socially and financially” (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010, p.44). This definition acknowledges the multi-dimensional nature of rehabilitation but given that the term “highest level” is value-laden, interpretations of rehabilitation vary both between professional bodies and models of health mirroring conflicting societal views relating to the person, disability and the role of health professionals (Young, Brown, Forster, & Clare, 1999). This will be considered further in Chapter 5.

1.4 Thesis structure

Chapter Two provides the background to this research topic, providing a summary of existing literature focused on embodiment, stroke rehabilitation, and transitioning from hospital. A justification for the need for further understanding of the embodied experience of stroke is also provided.

Chapter Three describes the rationale for the choice of a constructivist approach using the qualitative methodology of grounded theory. The method for participant recruitment, data collection, data analysis and techniques to enhance scientific rigour are explained in this chapter.
Chapter Four provides a description of the substantive theory developed from analysis of the data of participants. Here the embodied experience of stroke survivors transitioning from hospital is constructed and summarized from emergent themes.

Chapter Five is a discussion of the study findings including a comparison with existing understanding of the embodied experience of stroke. The significance of this research for physiotherapy practice is considered, and future directions for research and implications for clinical practice are suggested. Finally, Chapter Six summarises the key findings and concluding remarks on their relevance to stroke rehabilitation and physiotherapy are made.
Chapter 2: Background

2.1 Introduction

The effects of stroke for individuals can be profound with sudden, usually multidimensional, changes in stroke survivors’ life situations. Rehabilitation is often offered to stroke survivors to minimize the impact of stroke and support return to usual life situations. Life after stroke, including the rehabilitation process, will be a unique experience for each person. Physiotherapy is one aspect of rehabilitation which serves to develop, maintain and restore maximum movement and functional ability throughout the lifespan (World Confederation for Physical Therapy, 2014). The development of scientific knowledge of stroke physiotherapy has advanced significantly over recent decades with research focusing on the effects of physiotherapy interventions (Higgs, 2001; Intercollegiate Stroke Working Party, 2008; Maher, Moseley, Sherrington, Elkins, & Herbert, 2008; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010; Wikström-Grotell & Eriksson, 2012). However, the profession, both within stroke and other specialties, has been criticized for being dominated by a biomedical perspective (Nichols & Gibson, 2010) which limits the adoption of person-centred rehabilitation (Roberts, 1994), suggested in international stroke guidelines to be critical to the best rehabilitation outcomes for people with stroke (Intercollegiate Stroke Working Party, 2008; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010).

rehabilitation approaches aimed at increasing physical activity post-stroke to promote functional recovery, facilitating return to life-roles and reducing cardiovascular risk factors. Extensive research supports best practice for the physical effects of stroke including the promotion of walking, upper limb use and exercise (Gordon et al., 2004; Intercollegiate Stroke Working Party, 2008; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Physically focused evidence-based interventions include repetitive task training (French et al., 2009), strengthening (Ada, Dorsch, & Canning, 2006), cardio-vascular exercise (Pang, Eng, Dawson, & Gylfadóttir, 2006) and sensory retraining (Carey & Matyas, 2005). These approaches, although diverse in the target body structure, all promote bodily movement (Wikström-Grotell & Eriksson, 2012). Thus the body is central to stroke physiotherapy rehabilitation. As well as physical changes following stroke there may be non-physical changes, such as psychological and social changes, which also impact on the recovery process for stroke survivors (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). Many studies have explored these non-physical factors, especially in the context of the transition from hospital to the community when the full impact of stroke on life roles and living circumstances are at its most apparent (Cott, Wiles, & Devitt, 2007; Rittman et al., 2004; Salter, Hellings, Foley, & Teasell, 2008; Turner, Fleming, Ownsworth, & Cornwell, 2008). However, generally people’s experiences after stroke are divided into either physical or non-physical changes, and the entire embodied experience for stroke survivors is not yet fully understood (Faircloth, Boylstein, Rittman, & Young, 2004a).

Experiences of loss (Salter et al., 2008), uncertainty (Ellis-Hill et al., 2009; Salter et al., 2008), social isolation (Salter et al., 2008; Turner et al., 2008), lowered self-esteem
(Wood, Connelly, & Maly, 2010), and identity changes (Cott et al., 2007; Wood et al., 2010) have all been reported by stroke survivors transitioning to the community from hospital. The process has been described as a chaotic and stressful period for stroke survivors (Ellis-Hill et al., 2009; Salter et al., 2008; Turner et al., 2008). A resounding theme across studies is the all-encompassing nature of stroke. More specifically, a number of studies describe how stroke survivors have found their body to be “unfamiliar” (Kitzmüller et al., 2013, p.24) or separate from themselves (Faircloth et al., 2004;). The attention stroke survivors’ body demands of them has also been highlighted (Kitzmüller et al., 2013) with their body being described as risky (Ellis-Hill, Payne, & Ward, 2000) or “demanding” (Kvigne & Kirkevold, 2003, p.1300). At the time of transition from hospital to home ongoing changes have been described in the interaction between bodily perception, participation in everyday life and sense of self as stroke survivors move between the different contexts of hospital and home (Arntzen & Elstad, 2013). The embodied experience of stroke may also be changeable at this transitional time although little research has as yet explored this.

The World Health Organization (2001) advocates for the holistic and multi-dimensional consideration of people with all health conditions, viewing health from body, individual and societal perspectives (World Health Organization, 2001). Given that a third of strokes result in permanent disability (World Health Organization, 2002) there are potentially a significant number of stroke survivors learning to exist in a changed body. Their changed body is likely to impact on more than just physical abilities. Previous studies have also suggested physical changes after stroke influence a person’s sense of self
identity, often being situation dependent (Ellis-Hill et al., 2000; Faircloth et al., 2004; Kitzmüller et al., 2013). Clearly the effects of stroke on people’s physical activity cannot be adequately understood from a single, physically-orientated, vantage point typical of physiotherapy (Nicholls & Gibson, 2010).

2.1.1 Researcher perspective

As a physiotherapist working in stroke rehabilitation, I have become increasingly interested in the journey that stroke survivors take in their recovery. In particular it interests me how resilience can be born in the face of stroke adversity and, as a health care professional, how I can contribute to that. The service I work in is interdisciplinary, and strives for a person-centred approach to rehabilitation (Canterbury District Health Board, 2009a). However, my training, professional culture and rehabilitation approach still, I feel, promote the compartmentalizing of people into specific parts or aspects of stroke survivors experience, such as ‘mobility’ or ‘arm function’, with an objectifying and mechanistic view of people. More specifically within physiotherapy, there is often a disproportionate focus on physical symptoms in my experience.

I moved to New Zealand from the United Kingdom seven years ago having graduated as a physiotherapist there in 2004. I have spent nine years working with people with neurological conditions and seven of those years in community stroke services in the role I am currently in. As a physiotherapist I have witnessed a vast range of responses to people having a stroke. I have been particularly struck by the way some people have gone
on a journey of rediscovering their own bodies after having a stroke. This, for some, has been a positive process with resilience predominating, but for others a bitter process of grieving for the body they have lost. Similarly it has fascinated me how some stroke survivors objectify their own body. This can extend to people giving their hemiplegic arm a name and ‘telling off’ this ‘person’ when their arm fails to perform in the way they would like. This division of self and viewing the body as an object made me wonder how this impacted on their participation in rehabilitation. Moreover, I postulated the significance of a changed body on their self-identity.

Another growing point of interest for me has been the disparate responses people have of being seen by friends, family and strangers in their post-stroke body and potentially with adaptive aids such as walking frames. At times perplexed, their response seemed disproportionate for their level of impairment and has been frustrating for me as a physiotherapist. For instance, a woman who had standing balance problems following a cerebellar stroke who was hugely upset at not being able to wear high heels whilst dancing, to the point where she chose to retire from dancing; something she had been passionate about prior to her stroke. This individual experience and adjustment after stroke has been acknowledged by a number of authors (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004b; Murray & Harrison, 2004; Salter et al., 2008) but is not something which I had been exposed to during my undergraduate training. Instead the focus of my training, which is comparable to the New Zealand physiotherapy training content, was on the biomedical influences on health and recovery. At times, this training appeared to me to be inadequate.
to make sense of some stroke survivor’s experiences after stroke and impacted on my ability to provide physiotherapy rehabilitation.

The Community Stroke Rehabilitation Service, where I currently work as a physiotherapist, reports attaining good outcomes in terms of patient goal attainment and reducing impairment levels (Canterbury District Health Board, 2009a). However, patient surveys indicate stroke survivors have a poor understanding of stroke and low activity levels (Canterbury District Health Board, 2009b). Although the Community Stroke Rehabilitation Service aims to foster a person-centred approach to improve independence it is possible that stroke survivor’s problems are still compartmentalized into specific disciplinary issues. In particular, physiotherapy is predominately focused on remediation of physical abnormalities, focusing on the physical changes of stroke and viewing the body as a physical entity. It is in the role of physiotherapist that I have developed a desire to improve understanding of the experience of living in a changed body following a stroke and explore what this means for the individual. On a personal level I hoped that increased understanding would direct my physiotherapy practice to improve outcomes, rehabilitation effectiveness, and most importantly the journey for stroke survivors. For the physiotherapy profession I hoped that this research may inform an enhanced understanding of embodiment in stroke survivors in ways that advance physiotherapy theory to adopt a more holistic approach to stroke rehabilitation.

The aim of this study is therefore to improve understanding of stroke survivor’s experience of transitioning home with a changed physical body. The remainder of this
chapter provides a background of what is already known about embodiment after stroke and highlights the limitations of this knowledge in relation to physiotherapy.

2.2 Embodiment

Embodiment distinguishes between the objective body, where the body is regarded as a physiological entity, and the phenomenal body, where the body is not just a physiological entity, but my (or your) body as I (or you) experience it (Merleau-Ponty, 1962). Thus embodiment encompasses a holistic view of a person whilst rejecting reductionist views of the body (Nicholls & Gibson, 2010). Historically, in the medical model of health, there has been a suggestion of a mind-body dualism in which the body can be considered as a “machine” (Roberts, 1994, p.364). This ontological approach to the body was perhaps most famously advocated by the 17th-century philosopher Rene Descartes in his theory of Cartesian dualism where subjective and objective experiences were separated (Goldberg, 2011). The prevalence of this concept is apparent in the division of health care professions into dealing with either the body or the mind, with physiotherapy clearly focused on the physical body (Roberts, 1994). The mind-body dualism has since been largely rejected, including by Merleau-Ponty who argued that embodiment is the core principle of human existence with the body being both uniquely subject (the lived body) and object (the observed body) (Goldberg, 2011). However, the physiotherapy profession, though acknowledging the interconnection of body and mind, still works from an assumption that physiotherapists will focus on the physical body and other professions will consider the mind (Mudge, Stretton, & Kayes, 2013; Nicholls &
Gibson, 2010; Roberts, 1994). My experiences as a physiotherapist working with people following stroke, indicates this dualistic view of the body and mind is negatively affecting physiotherapy practice.

The concept of embodiment in health and disability, especially in terms of stroke and physiotherapy, is poorly developed (Nicholls & Gibson, 2010). Despite ‘bodies’ being at the core of physiotherapy practice there is very little theoretical exploration of the body as a whole and as the medium through which we experience the world. This is in part due to the biomedical foundations from which physiotherapy practice grew in late Victorian England (Nicholls & Gibson, 2010; Roberts, 1994). A professional distance between patients and physiotherapists was proactively cultivated by endorsing the body as an object or machine to enable intimate touch to be culturally acceptable without any sexual connotations (Barclay, 1994). Despite approaches to health and disability advancing from this time, there is limited corresponding development around the concept of the body and embodiment in physiotherapy practice (Jorgensen, 2000). It is my view that this stance is limiting for some areas of physiotherapy practice including stroke and other chronic health conditions.

Conceptualizations of the body vary greatly among health related disciplines with the notion of embodiment being variably defined and embedded in theoretical models and clinical practice to differing degrees. For example, fundamental to the biomedical model which underpins medical practice is the assumption of body-workings as being either normal or abnormal (Roberts, 1994). This concept of normality has been contested by the
disability movement due to the negative connotations of being “abnormal” and the implications of using personal judgment to ascertain “normality” (Roberts, 1994, p.363). Medicine’s body-ontology has also been criticized for being a ‘dead’ body, with objectification of people’s bodies being engrained in practice (Slatman, 2014). Although medical practice is increasingly touting person-centred care, embodiment does not yet feature in theoretical models of health (Slatman, 2014), rather the body is still represented within practice and literature in dis-embodied compartments.

Likewise, in nursing, embodiment remains poorly defined despite the term being utilized increasingly in nursing research (Thomas, 2005; Wilde, 1999). Like physiotherapists, nurses often provide intimate care to people’s bodies and strive to take a holistic approach to health care (Mason, 2014). However, the body arguably remains silent because nurses are not actively involved in the development of embodiment as a paradigm for practice (Mason, 2014; Thomas, 2005; Wilde, 1999). Consequently embodied meanings of illness are under-acknowledged and the human body remains submissive in nurse-patient relations (Thomas, 2005; Wilde, 1999).

Conversely, embodiment concepts are more established in the area of psychology, and to some degree social work and occupational therapy practice. For instance, in social psychology embodiment has been referred to as the “assumption that thoughts, feelings and behaviours are grounded in sensory experiences and bodily states” (Meier, Schnall, Schwarz, & Bargh, 2012, p.706). Psychological approaches related to embodiment are engrained in practices such as addressing how physiological arousal affects emotions, and
temperatures influence behaviour (Kiverstein, 2012; Meier et al., 2012). Similarly, bodily ability has been shown to influence individuals’ perceptions of the world around them. For example, elderly people and others with declining health have been found to perceive hills as steeper, reflecting their decreasing ability to climb hills (Bhalla & Proffitt, 1999). Despite this knowledge, theories of embodiment, especially in relation to health and disability remain primarily descriptive rather than explanatory in social psychology (Meier et al., 2012).

In social work practice, embodiment theory is more widely acknowledged, although a more complex understanding of the interconnectedness of the body is desired by scholars in the hope to better understand people’s individual experiences as well as broader social conditions such as discrimination (Bell, 2011; Tangenberg & Kemp, 2002). For example, social work is said to strive to understand and recognize the complexities of diversity and social equity, encompassing the experience of difference. This includes experiences of difference within the body, which serves both as an external marker, such as age, race, gender, ability, and sexuality, as well as an internal experience (Tangenberg & Kemp, 2002). However, in contrast to physiotherapy practice, it has been argued within social work literature that the body has been historically under-recognized in social work practice, especially as a construct for self, social identity and power (Tangenberg & Kemp, 2002). Although suggestions have been made for potential frameworks of practice (Tangenberg & Kemp, 2002), such as considering the body as a physical, societal and relationship medium, a linear and biomedical focus for social work practice reportedly prevails (Bell, 2011).
Disparately occupational therapy models are focused on how people occupy themselves with individuals generally viewed as a whole in relation to a given occupation or activity (Stamm, Cieza, Machold, Smolen, & Stucki, 2006). ‘Participation’ and ‘person-centred practice’ are central to occupational therapy theory and practice, with a focus on eliminating environmental barriers to maximise independence with activities of daily living. However, occupational therapy academics have still reported the discipline lacking theoretical models that explicitly acknowledge embodiment (American Occupational Therapy Association, 2002; Thibodaux, 2004). In particular, occupational therapy professional knowledge and ideas about disability have been criticized due to a perceived over-reliance on “outsiders” perspectives rather than exploring people’s lived experienced of disability (Thibodaux, 2004, p.508).

The lack of understanding of embodiment theory in health and disability may be due, in part, to a lack of common philosophical language to link these isolated professional theories. Furthermore, the links of the embodied experience to health and disability are as yet grossly under explored amongst healthcare professionals. The World Health Organisation’s International Classification of Functioning, Disability and Health (ICF; World Health Organization, 2001) provides a common language for inter-professional understanding of health conditions with impairments, function and participation being integrated into one model. The ICF also considers contextual factors such as the environment and personal influences. However, the ICF does not acknowledge the subjective experience or social engagement (Wade & Halligan, 2003), both of which are
fundamental to the embodied experience. Consequently there is potential for inter-disciplinary theory development of embodiment and how embodied experiences relate to health and disability.

2.2.1 Embodiment in stroke

The focus on the embodied experience of stroke is broad, with relatively few studies conducted. Table 1 provides a narrative summary of articles which have the bodily experience of stroke as a primary aim of study. The scope/limitations with regard to my research question have been briefly identified and will be further considered in the following sections.
Table 1: Summary of key articles which consider the embodied experience of stroke survivors as a primary aim

<table>
<thead>
<tr>
<th>Reference</th>
<th>Focus of study</th>
<th>Methodology and strategies for rigour</th>
<th>Participants</th>
<th>Key Findings</th>
<th>Scope and limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arntzen, Hamran &amp; Borg (2014)</td>
<td>Explored stroke survivors’ experiences of their body, participation and self when moving from institutional rehabilitation to home</td>
<td>Phenomenological hermeneutical • Field notes • Peer meetings • Stated background of primary researcher • Use of literature explicit • Extended interview extracts to substantiate findings</td>
<td>Nine stroke survivors and their close relatives interviewed at one to three weeks after stroke or education programme, and again at six months</td>
<td>Stroke influenced participant’s perception of their body, sense of self and participation. As an in-patient participants described feeling they were in a good place whilst they felt vulnerable. This environment “shielded” (p.10) them with hope of recovering the physical body being all-absorbing at this time. After discharge home participants described uncertainty with their sense of self feeling fragmented. They described having to negotiate and change participation in everyday life.</td>
<td>Retrospective and convenience sampling in disparate settings. This may be due to this study being part of a broader study which may have influenced the approach taken.</td>
</tr>
<tr>
<td>Ellis-Hill, Payne &amp; Ward (2000)</td>
<td>Explored the life narratives of people after stroke including constructing meaning and issues of identity in physical recovery.</td>
<td>Life narrative approach • Explicit recruitment process • Field notes • Peer coding • Acknowledged relationship between participants and researcher</td>
<td>Eight stroke survivors interviewed as in-patient, six months and one year</td>
<td>All participants described a fundamental change like entering a new world. They described their body as separate and precarious being perplexing and unreliable to them. They also described a changed body, social self-body relationship. There were ongoing issues at one year especially physical activity in community which was restricted by participants increased awareness of physical limits</td>
<td>Focus on stroke within participant’s life story, broader than embodiment. Participants are a subset from a larger study.</td>
</tr>
<tr>
<td>Faircloth, Boylstein,</td>
<td>Explored recovery and</td>
<td>Unclear. Semi-structured interviews part of a larger observational study</td>
<td>51 stroke survivors one</td>
<td>Participants described managing their body within a mind-body dualism with a sense of</td>
<td>Observational study from a larger mixed study</td>
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<td>Reference</td>
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<tr>
<td>Rittman &amp; Young (2004a)</td>
<td>bodily perceptions at relatively early stage post-stroke study. Strategies for rigour not stated</td>
<td>month post-discharge home</td>
<td></td>
<td>the body being a passive/foreign object. At other times though participants described their body as an active/familiar object. Participants “tested” (p.78) their body in everyday situations in order to help create coherence in their “biographical body” (p.80)</td>
<td>method multisite project - process of data analysis unclear</td>
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| Kitzmuller, Haggstrom & Asplund (2013) | Explored the significance of the long-term influence of bodily changes on the perception of self | Phenomenology-hermeneutic approach  
- Field notes  
- Coding process explicit  
- Extended interview extracts to substantiate findings | 23 chronic stroke survivors (over 3 years after stroke) | Stroke forced participants to adjust to a suddenly altered body that felt fragile. This caused participants to live with increased attention to their bodily functions. This lost control over their body caused feelings of strangeness and a sense of “living in a body that is not me” (p.24). Highlighted the importance of perception of self in bodily experiences. | Captures life-long dynamic nature of embodied experience, but does not capture transitions in experiences early after stroke |
| Kvigne & Kirkevold (2003) | Explored how women experienced their bodies after stroke                      | Phenomenology study                  
- Theoretical framework stated  
- Explains strategies for developing relationship between participants and researcher  
- Coding process clearly explained | 20 women post-stroke at six weeks, six months and one year | Participants linked current bodily experiences with their past and future. The bodily experience after stroke was described as unpredictable, demanding, and a sense of an extended body. Identified profound disturbing experiences of a changed body after stroke with a dynamic process as people moved from bodily strangeness towards “re-embodiment” (p.1304) | Data collected over one year capturing how embodied experiences changed over time. Strong focus on feminism although no comparison with men |
The studies which have been completed, although having varied foci, overlap in a number of the concepts identified that relate to embodiment (Arntzen & Elstad, 2013; Ellis-Hill et al., 2000; Faircloth et al., 2004a; Kitzmüller et al., 2013; Kvigne & Kirkevold, 2003; Pallesen, 2014). I have summarised these concepts as: a self-body split, an altered bodily awareness, an altered perception of self, social context, and dynamic self-body relationship.

*Self-body split*

A common notion amongst studies of the bodily experience of stroke was having a body which felt different and separate to their sense of self. This difference in the post-stroke body has been associated with different labels in various studies but can be summarized as a body which feels (a) foreign, (b) out of control, (c) fragile, and (d) disliked. The foreignness of the post-stroke body is perhaps the most striking and common theme in interviews with stroke survivors. For example, Ellis-Hill, Payne and Ward (2000) identified how stroke survivors interviewed at six and 12 months after their strokes described a changed relationship with their bodies. Participants expressed their body as being precarious and separate from their sense of self. Similarly Faircloth, Boylstein, Rittman and Young (2004a) described how stroke survivors referred to their body as a passive, foreign object when interviewed one month after leaving hospital. This led to participants having to “listen” to what their body was “telling” them, with a feeling of a mechanized body, separated into parts (p.75). This alienation of the body has also been described in the early stages after stroke whilst people are still in hospital with participant’s
perceiving their bodies in a fragmented way (Arntzen, Hamran, & Borg, 2014). Thus a separateness between the self and the physical body appears to be a component of the embodied experience of stroke.

Stroke survivors’ perception of their body as foreign may be in part due to the lack of control many have described. This lack of control has been associated with a body that is unpredictable (Kvigne & Kirkevold, 2003), perplexing (Ellis-Hill & Horn, 2000) and unreliable (Kitzmüller et al., 2013; Pallesen, 2014), and is often associated with frustration (Pallesen, 2014). The sense of a foreign and uncontrollable body suggests a detachment between the stroke survivor’s sense of self and their body. This self-body split is reinforced by stroke survivors often objectifying their own bodies (Ellis-Hill et al., 2000; Faircloth et al., 2004a). In interviews with chronic stroke survivors these perceptions have amounted to people describing living in a body “that is not me” (Kitzmüller et al., 2013, p.24).

Bodily symptoms such as pain and weakness, combined with lack of control, have been suggested as further contributing to stroke survivors perceiving their body differently, for example, as fragile (Kitzmüller et al., 2013) or vulnerable (Kvigne & Kirkevold, 2003). As a result, the body has been seen as limiting for stroke survivors, and caused them to question the continuity between themselves and what their body will allow (Arntzen et al., 2014). This separation can be such that stroke survivors have developed a dislike of the affected side of their body (Loetscher, Regard, & Brugger, 2006) and have a negative relationship with their own body (Kitzmüller et al., 2013). Thus it is common for stroke
survivors to have a changed relationship with their bodies, often viewing their body as passive and separate to their sense of self.

*Altered bodily awareness*

In addition to a changed relationship with their bodies, many stroke survivors alluded to an altered awareness of their bodies; with a body that ‘demanded’ their attention in particular situations. Over time stroke survivors described being at ease with their changed body to the point where they were often no longer consciously aware of these changes in their everyday life (Ellis-Hill et al., 2000). However, in new or social situations participants described becoming acutely aware of their body (Ellis-Hill et al., 2000; Kitzmüller et al., 2013; Kvigne & Kirkevold, 2003). This was at times due to a changed physical appearance (Kvigne & Kirkevold, 2003), or because a heightened awareness of the body was required for functional tasks such as walking (Ellis-Hill et al. 2000) or dressing (Kitzmüller et al., 2013). As a result stroke survivors have been described to experience their body as a negative and demanding entity, which directs many of their behaviours and determines the meaning of their physical experience (Ellis-Hill et al., 2000; Kitzmüller et al., 2013; Kvigne & Kirkevold, 2003).

In unproblematic and healthy conditions the body is said to “dys-appear” (Leder, 1990, p.26) or be “silent, taken for granted” (Bleeker & Mulderij, 1992, p.2). A person may experience their body as ‘re-appearing’ such as during sporting activities, with an enjoyment of increased bodily awareness (Zeiler, 2010). However, when the person is
faced with problematic situations such as with disability, the body is said to reappear in an unpleasant manner. Leder (1990) termed this “dys-appearance” (p.26) with the ‘dys’ meaning ill or bad. This dys-appeared body is characterized by being apart and ‘alien’ but also demands more attention from the subject than ever before. This attention has been described both as conscious and forced. For instance stroke survivors often described consciously looking for signs of potential problems and trying to actively gain understanding of their perplexing body via health care professionals (Ellis-Hill et al., 2000). For others, the heightened bodily awareness was forced as they attempted to achieve smooth functioning (Kitzmüller et al., 2013). This attention has been suggested as context specific, with certain situations demanding more attention than others (Ellis-Hill et al., 2000; Kitzmüller et al., 2013). Thus the post-stroke body was experienced as demanding energy-consuming attention and direction from a seemingly separate self (Ellis-Hill et al., 2000). Furthermore, the novelty and complexity of the context in which a person attempted to use their body is apparent.

Altered perception of self

Stroke can have a profound effect on self-identity with selfhood frequently being questioned by stroke survivors (Ellis-Hill & Horn, 2000; Murray & Harrison, 2004). Self-identity is defined as “a dynamic collection of self-representations, which are formed through personal experiences, and interpretation of the environment” (Ellis-Hill & Horn, 2000, p.280). The embodied self is only one part of one’s self-identity, but self-identity forms a part of embodiment. The perception of self is also, at least in part, socially
constructed comprising of aspects such as roles, social positions, preferred activities and appearance (Gelech & Desjardins, 2010). It is also constructed intrinsically in how we see ourselves in terms of traits and values (Gelech & Desjardins, 2010). For stroke survivors who have experienced a loss in any one of these domains, “who am I?” is a question frequently evoked (Kitzmüller et al., 2013, p.24). Thus an altered body can cause stroke survivors to question their selfhood and existence.

Furthermore, many stroke survivors have grappled with their altered perception of self due to a changed physical body, such that their own personhood could have an unfamiliarity to them (Ellis-Hill & Horn, 2000; Kitzmüller et al., 2013; Murray & Harrison, 2004). Murray and Harrison (2004) identified a “profound loss of self” (p.810) by stroke survivors they interviewed over two years after their stroke, with an apparent detachment from their “new” selves (p.811). This is particularly confusing for stroke survivors where there is a mismatch between what they considered themselves to be and what their post-stroke body allowed them to be (Arntzen & Elstad, 2013; Kitzmüller et al., 2013). These bewildering and negative perceptions of body and/or self have been commonly associated with loss of confidence and grief in a number of studies of stroke survivors (Ellis-Hill & Horn, 2000; Kitzmüller et al., 2013; Murray & Harrison, 2004). Furthermore, the degree of deterioration in self-concept does not necessarily correlate with physical ability (Ellis-Hill et al., 2000). For instance stroke survivors with less visible problems such as fatigue, or loss of confidence expressed questioning their self-identity, and feeling frustrated at being unable to express these more ambiguous experiences to
others (Ellis-Hill et al., 2000; Kitzmüller et al., 2013). Consequently it appears the relationship between the embodied self and physical changes after stroke is complex.

**Social context in embodiment**

The self-body relationship of stroke survivors has also been reported as being socially dependent. For example Ellis-Hill, Payne and Ward (2000) found some stroke survivors felt quite comfortable with their body in the company of close family and friends. However, in the community their body became “the focus of social gaze and lost its silence” (Ellis-Hill et al., 2000, p.730). This caused participants to withdraw from public scrutiny and spend increased time at home (Ellis-Hill et al., 2000). This sentiment was echoed by participants in a study by Murray & Harrison (2004) where physical presentations that are ambiguous to lay public, such as ataxia and use of aids, served as barriers to social interaction because they created a discord between people’s perception of how they looked, and who they perceived themselves to be (Murray & Harrison, 2004). Consequently the self-body relationship is influenced by, and in turn influences, the social context of people after stroke.

**Dynamic self-body relationship**

Embodiment after stroke is a dynamic process with people’s experiences of their bodies changing over time. The process has been described as re-embodiment where stroke survivors describe becoming gradually familiar with an unfamiliar body (Kvigne & Kirkevold, 2003). This re-embodiment process has been considered at various stages of
life after stroke including as an inpatient (Arntzen et al., 2014), one month after discharge from home (Faircloth et al., 2004a), and up to one year after stroke (Ellis-Hill et al., 2000). Previous studies appear unanimous in stating that the embodied experience is a dynamic process, but the trajectory of this re-embodiment remains unclear. For instance Faircloth et al. (2004a) described how subjects sought to “create coherence in the biographical body” (p.80) whereby meaning and future projections of self were developed and linked with past self-perceptions and experiences. However, stroke survivors have also expressed conflict in their self and body one year after their stroke (Ellis-Hill et al., 2000) suggesting they had not been able to create coherence or at least that this relationship remained unresolved. This process of adjustment has instead been considered as a life-long process of adaptation (Kitzmüller et al., 2013) although some researchers have explored influential events such as transitioning from hospital to home and view these events as pivotal in peoples embodied experiences (Arntzen et al., 2014). Thus it appears a temporal and responsive shift in the embodied experience may occur after stroke that is not yet fully understood.

A number of social indicators have been identified as accounting for the extent of this disrupted biographical flow including age, gender, other health concerns and previous knowledge of the illness experience. For instance Faircloth et al. (2004b) identified how stroke survivors could normalise some of the limiting effects by attributing it to the ageing process. Similarly Kitzmuller et al. (2013) identified how the impact of stroke on self-perception varied according to life stage with those losing their jobs as a result of their stroke being more affected in terms of selfhood than a retired stroke survivor. Gender differences have also been considered as significant in the self-body relationship. For
instance Kvigne & Kirkevold (2003) specifically explored women’s experiences and considered how appearance can often be socially and personally more important for women than men. This notion was mirrored by Charmaz (1995) who contended that appearance may be more important to women, but proposed that women also tend to adapt to illness better (Charmaz, 1995). Thus the relationship between body and self after stroke appears to be dynamic, being influenced by a number of factors, but this relationship in people’s embodied experience is not yet fully understood.

2.2.2 Embodiment in chronic illness

Embodiment has been explored in relation to a number of other chronic health conditions. The understanding gained from people with other health conditions may inform considerations for the post-stroke experience because, while stroke is a one off neurological event, the sequelae essentially constitute living with a chronic condition. The unity of body and self is thought to be frequently disrupted in other chronic health conditions as has been described after stroke. Drawing on qualitative research with people living with chronic health conditions, Charmaz (1995) proposed that bodily alienation caused by illness disrupts a person’s assumptions of the relationship between their body and self and therefore their sense of wholeness. However, Charmaz (1995) suggested that a familiarity with the body develops over time. Changed identity goals may also emerge which may include trade-offs to avoid situations that threaten the established sense of self. Charmaz (1995) argued these trade-offs include “surrendering” (p.672) to their sick body whereby they stop pushing bodily limits and affirm that their self is inextricably linked to
their sick body (p.672). These embodied experiences appear comparable to those expressed by stroke survivors in the literature exploring concepts of self and body.

Similarly the changed relationship between body, self and the world has been considered in chronic pain (Bullington, 2009; Zeiler, 2010). In the presence of chronic pain, a multi-dimensional phenomenon, the perception of people’s world may narrow, the body becomes illness and there may be a lost sense of self (Bullington, 2009). Bullington (2009) considered how the physical body is usually in the background of our lives yet comes to the foreground in the presence of pain, so people “become pain” (p.106) resulting in the experience of alienation from others, not in pain, around them. Additionally an experience of body “listening” and altered bodily awareness has been described in the presence of pain (Zeiler, 2010, p.336). Thus the embodied experience of chronic pain may mirror that of stroke whereby the body and self can be perceived as split, and connections with society altered.

Likewise, the altered bodily awareness which stroke survivors have expressed is echoed in other chronic health conditions. For instance, Price (1993a) interviewed adults with multiple sclerosis and asthma and asked them to keep a diary for six weeks to understand their body experience in comparison to healthy individuals. She found that those with chronic health conditions had an increased awareness of their bodies and this directed their behaviours, whilst holding meaning for their physical experience (Price, 1993a). This was in contrast to healthy individuals who described their body experience as “a function taken for granted” (Price, 1993a, p.46). This study built on a previous study of
diabetic adults who learnt to “listen” to their body in order to understand their disease (Price, 1993b, p.37). Therefore it appears a number of chronic health conditions influence bodily awareness, a component of the embodied experience, in a similar way to stroke.

Similarly, factors which may influence the embodied experience have been considered in other health conditions. For instance Clarke and Griffin (2008) explored body image in people aged over 68 years with greater than five health conditions. They alluded to the embodied experience being shaped by cultural ideals and related this to “successful ageing” (Clarke & Griffin, 2008, p.1084). The embodied experience has also been specifically considered for men and women separately (Kvigne & Kirkevold, 2003; Sparkes & Smith, 2002). For example, Sparkes and Smith (2002) considered how “alien” (p.259) body-self relationships prompted anxieties around the loss of masculinity and athletic identities in men who had sustained a spinal cord injury. Likewise, social expectations and femininity were considered by Kvigne and Kirkevold (2003) when interviewing women who had sustained a stroke. Kvigne and Kirkevold (2003) referred to Leder’s terminology, bodily “dys-appearance” (Leder, 1990, p.26), arguing that this experience may be even more pronounced for women, for whom bodily appearance may be culturally more significant than for men. Additionally the embodied experience has been considered in relation to assistance aids such as wheelchairs and walking frames. For instance, walking aids made older people feel they were being perceived as vulnerable and dependent (Brännström, Bäckman, & Santamäki Fischer, 2013) and wheelchairs have been expressed both as a physical barrier to accessing social environments, as well as impacting on social self-identity (Papadimitriou, 2008). These studies support the notion that the
embodied experience of health conditions is deeply entwined in self-identity and social relationships.

2.2.3 Embodiment and physiotherapy

To date, there are few studies specifically considering physiotherapy and the embodied experience of chronic health conditions. Of the existing studies on embodiment and physiotherapy, much of the research originates from the field of chronic pain (Bullington, 2009; Zeiler, 2010), mental health conditions (Fuchs & Schlimme, 2009; Williams, 2000), ageing (Charmaz, 1995; Clarke & Griffin, 2008; Price, 1993), and traumatic brain injury (Sivertsen & Normann, 2014). The majority of studies exploring the embodied experience of stroke and other health conditions have been conducted by scholars in the area of social psychology or health philosophy. There appears to be an unacknowledged division between the biomedical aspects of health conditions and the psycho-social aspects within physiotherapy, with the marrying of these two seeming challenging. Nicholls & Gibson (2010) suggested that historically too much emphasis has been placed on the biomechanical view of the body, and challenged physiotherapists to also consider the body in terms of the self and societal body, meaning that people’s perceptions of their body is, in part, shaped by cultural, economic, political and social influences.

Physiotherapy approaches vary in focus from the early stages of stroke recovery, usually during hospital stay, to returning home and then longer-term needs (Kwakkel et al.,
There is consensus that for the majority of people with stroke neuroplasticity is at its most rapid during the first few months after stroke and therefore recovery mostly occurs during this time (Bamford, Sandercock, Dennis, Warlow, & Burn, 1991). However, physical gains can occur for people throughout life, with evidence for physical progress in people many years after their stroke (Ferrarello et al., 2011). Similarly, the approaches of services are also varied with research evidence supporting community-based stroke specialist services (Legg & Langhorne, 2004; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010; Van Der Bij, Laurant, & Wensing, 2002), monodisciplinary outpatient services (Britton & Andersson, 2000) and group based therapy (Wevers, van de Port, Vermue, Mead, & Kwakkel, 2009). Although home based rehabilitation is recommended in the New Zealand Clinical Guidelines for Stroke (2010), no one approach in isolation is advocated and a combined, person-centred approach is recommended (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010).

Given the diversity of stroke effects, stages of recovery and potential settings, best practice physiotherapy for stroke can be considered dependent on individual client presentations and circumstances. However, clinical research for stroke physiotherapy to date is predominately related to the biomedical view of the body and physiotherapy approaches are focused on the physical body such as exercise therapy, walking interventions, task repetition, sensory retraining, provision of aids and education (Tyson, Connell, Lennon, & Busse, 2009; Van Der Bij et al., 2002; Van Peppen, Hendriks, Van Meeteren, Holders, & Kwakkel, 2007).
There has been criticism of the physiotherapy profession for its lack of theoretical evolution generally (Cott et al., 1995; Nicholls & Gibson, 2010) and hyper-focus on physical function (Sarre et al., 2013) across all health conditions. There is a lack of physiotherapy specific models of practice, and instead the profession is most commonly associated with generic models such as the ICF (World Health Organization, 2001) which acknowledges the multi-faceted nature of health, including personal and social factors. Some theoretical papers have attempted to consider professional models more specifically tailored to physiotherapy and a more multi-dimensional view of the body. For example, Wikström-Grotell and Eriksson (2012) discussed the concept of movement in physiotherapy, emphasizing the need for a more multi-dimensional understanding of movement instead of the historically biomedical focus. Wikström-Grotell and Eriksson (2012) summarized earlier research on the concept of movement in physiotherapy and identified movement as 1) intentional, 2) emotional, 3) having personal value or independency, and 4) an absolute value and sign of life, suggesting movement as having meaning beyond physicality.

A small number of studies have attempted to explore if this multi-dimensional view of the body and movement is taken by physiotherapists in practice. For instance, Jorgensen (2000) explored the concept of the body and health specifically in physiotherapy by conducting semi-structured interviews, and observing physiotherapists with orthopaedic patients (Jorgensen, 2000). They concluded that, despite physiotherapists believing they took a holistic approach, physiotherapy practice tended to reflect a very physical and instrumental concept of the body focusing on the anatomical body and overlooking
people’s lived experiences of their bodies. Similarly, Thornquist (1994) also considered
encounters between physiotherapists and patients, alluding to a dualistic consideration of
the body and mind in their examination and treatment. However, physiotherapists were
said to communicate with their patients as “embodied subjects” (p. 711) suggesting a gap
between theory and practice. This gap is echoed by others who suggest a contrast between
theoretical understandings and what actually occurs in practice, alluding to a lack of
consideration of ontological foundations by the physiotherapy profession (Noronen &

Physiotherapists are not alone in fragmenting the body when working with people
after stroke (Bendz, 2003) but given the increasing weight of evidence that the embodied
experience goes beyond the physical body it appears that there is a discrepancy between:

1. The predominantly biomedical theoretical models of physiotherapy and the
   clinical practice of physiotherapy for chronic health conditions such as stroke.
2. Theoretical basis to interventions used by physiotherapists and the health
   issues experienced by patients with stroke.
3. What physiotherapists perceive their approach to be and what they deliver.

It appears that if the embodied experience of stroke could be better understood and
integrated into physiotherapy theoretical models, interventions that extend beyond the
physical body could be developed. This may ultimately enhance outcomes for stroke
survivors by recognizing the encompassing nature of living with a changed physical body.
2.3 Stroke overview

2.3.1 Stroke pathology

The embodied experience of stroke may be, in part, related to the type of stroke a person has and the resulting impairments. Impairments may include motor loss, sensory loss, tonal changes, higher cerebral dysfunction, visuospatial disorders and movement disorders. Collectively these impairments can have a profound effect on the way a person perceives and relates to their body, which are aspects of embodiment. For instance, altered sensory-motor control, a symptom of many strokes, can cause a change in the ability to feel and move the body. For some stroke survivors there is altered feedback from the body of what is happening. This may result in disordered movement patterns such as ataxia (lack of voluntary coordination of muscle movements) or dyspraxia (altered planning of movements and co-ordination). Similarly visual-spatial and perceptual changes can significantly impact on how a person can move their body in space and in relation to their environment. Commonly stroke survivors experience weakness which can affect a person’s ability to move. These impairments often impact on the stroke survivor’s everyday function and participation in life roles (World Health Organization, 2001) as well as their relationship with their body (Faircloth et al., 2004a; Kvigne & Kirkevold, 2003). The extent that these physical changes influence a person’s embodied experience is unclear in the existing research (Arntzen & Elstad, 2013; Ellis-Hill et al., 2000).

Stroke survivors with these physical changes would typically be referred for physiotherapy assessment and intervention. Physiotherapists have been reported as
tending to focus on their biomechanical expertise, separating the body and minimizing the relevance of individual bodily experiences (Mudge et al., 2013). The incidence of altered bodily experience after stroke is unknown but likely to occur for the majority of stroke survivors, at least temporarily, given the incidence of physical changes (Feigin et al., 2014). However, existing research on the experience of stroke for people with a changed physical body suggests that learning to live with an altered body after stroke requires more than a biomechanical approach (Arntzen et al., 2014; Ellis-Hill & Horn, 2000). Greater understanding of the bodily experience of stroke could therefore usefully inform physiotherapy practice.

### 2.3.2 Epidemiology

Stroke and its effects are a globally significant issue. The prevalence of stroke is high with 33 million stroke survivors worldwide recorded in 2010 (Feigin et al., 2014). A recent extensive meta-analysis indicated that between 1970 and 2008 the incidence of stroke in low-income and middle-income countries had more than doubled in this timeframe (Feigin et al., 2014). Conversely in high-income countries there was a 42% decrease in stroke incidence. However, the absolute number of stroke survivors worldwide has increased by 84% since 1990, explained by the growth and ageing of our population. Stroke is a significant cause of long-term disability with approximately 50% of stroke survivors experiencing some degree of permanent disability (Department of Health, 2001). The risk of stroke increases with age with at least two thirds of strokes occurring in persons over 65 years of age (Department of Health, 2001). Risk factors for stroke include
hypertension, diabetes, atrial fibrillation, hypercholesterolemia, smoking, obesity as well as some iatrogenic factors (Donnan, Fisher, Macleod, & Davis, 2008). Stroke entails significant financial and societal costs. International expenditure studies of stroke indicate 3% of total health expenditure is spent on stroke (Evers et al., 2004). Similarly quality-adjusted life years\(^1\) has been calculated as a mean reduction of three years in moderate stroke (Tengs, Yu, & Luistro, 2001). Globally, despite some improvements in stroke incidence, the burden of stroke is increasing with a rise in disability-adjusted life years\(^2\) of 12% between 1990 and 2010 (Feigin et al., 2014). The burden of stroke is therefore of international significance both for individuals and on a societal level. Improved awareness of people’s experiences of health care conditions is important for guiding research, understanding complex issues and providing a person-first understanding (Dixon-Woods, Fitzpatrick, & Roberts, 2001). Insights into stroke survivors’ experiences of their body therefore have the potential to influence outcomes like Disability or Quality Adjusted Life Years for stroke survivors.

### 2.3.3. Stroke rehabilitation in New Zealand

One in 56 adults have had a stroke in New Zealand (Ministry of Health, 2008) with over 700 strokes annually in Canterbury, the location for this study (Canterbury District Health Board, 2009a). Lifetime costs per stroke survivor in New Zealand are estimated at $73,600 with a total cost to the country of over $450 million annually (Brown, 2009).

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\(^1\) Quality-adjusted life years is a measure of disease burden, including both the quality and the quantity of life lived

\(^2\) Disability-adjusted life years is a measure of overall disease burden, expressed as the number of years lost due to ill-health, disability or early death
Stroke services are based on National best practice guidelines (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010) and there can generally be considered to be an integrated stroke specialist pathway from acute management through to long-term community integration.

2.3.4 Overview of Christchurch stroke services

At the time of this study a stroke survivor who received treatment with the Canterbury District Health Board over the age of 65 years, or over 55 years if identifying as NZ Maori or Pacific Islanders, would be admitted to the Acute Stroke Unit at Christchurch hospital. This unit is operated by an acute medical and multi-disciplinary team who provide acute intervention, assessment and discharge planning. Stroke survivors who unable to function at home from the Acute Stroke Unit will be transferred to the Stroke Rehabilitation Unit at Princess Margaret Hospital. There a coordinated stroke specialist team would provide therapeutic intervention until either stroke survivors are able to function at home or their progress plateaus. On discharge from either the Acute Stroke Unit or Stroke Rehabilitation Unit the stroke survivor may then be referred to the Community Stroke Rehabilitation Service, where I work as a physiotherapist, if further rehabilitation potential is identified. Younger people who have strokes followed a different pathway of care outside of the service I worked, and were therefore not investigated in this particular study.
2.3.5 Biculturism and embodiment

New Zealand is a bicultural society comprising indigenous Māori people, and later immigrants of a range of ethnic origins. There are differing stroke demographic profiles for Māori and non-Māori stroke survivors, with unique cultural perspectives, which may influence stroke survivors’ experiences of their body. Ongoing health disparities exist between Māori and non-Māori populations (Feigin et al., 2006; Harwood, 2010) as well as disparities in experiences of health services (Dyall, Feigin, Brown, & Roberts, 2008). Culture has been suggested to influence people’s embodied experiences in that our cultural values influence our perceptions (Thomas & Wardle, 2014; Wilde, 1999). The mean age of first stroke is 61 years in Māori and 65 years in Pacific people, compared with 76 years among New Zealand Europeans (Feigin et al., 2006). Age has been suggested as a factor in the embodied experience (Faircloth et al., 2004a,b; Thomas & Wardle, 2014) therefore Māori people may have a unique embodied experience after stroke. The New Zealand Stroke Guidelines make recommendations for stroke services to be accessible and effective for all New Zealanders, irrespective of where they live, their age, gender or ethnicity (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010).

2.4 Life after stroke

Although controversy exists around the content of stroke rehabilitation and the philosophy that underpins it, there is growing consensus that the consequence of stroke in terms of a persons’ engagement in valued activities and social roles should be considered more in stroke rehabilitation than it currently is (Hartman-Maeir, Soroker, Ring, Avni, &
Katz, 2007; Robison et al., 2009; Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010). A person’s embodied experience is integrally related to their engagement in valued activities and social roles, although in what way is not yet fully understood (Arntzen et al., 2014; Faircloth et al., 2004a; Kitzmüller et al., 2013).

2.4.1 Participation in meaningful activities

It is widely acknowledged that many stroke survivors have significant restrictions in meaningful activities of daily living, socializing, occupations and recreation (Hartman-Maeir et al., 2007; Mayo, Wood-Dauphinee, Côté, Durcan, & Carlton, 2002; Robison et al., 2009). Physical impairments account for some of these restrictions (Wang, Mitchell, Smith, & Leeder, 1999) as do social constraints such as stigma and non-physical personal factors, such as mood (Pound, Gompertz, & Ebrahim, 1999). However, the influence of the embodied experience after stroke on non-physical personal factors and people’s participation in meaningful activities is less understood. Robison et al. (2009) who interviewed stroke survivors following discharge home, then again at one year, attempted to explore what helped people to resume previously valued activities. A number of factors including environmental influences, support from others, adaptability of the individual, and professional support were identified as influencing the resumption of valued activities. In terms of bodily experiences, Robison et al. (2009) identified people had a loss of confidence in their bodies, negative sensations when doing activities, less control of their body in unfamiliar environments, shame at appearing disabled and overall feeling like “a different person” (p.1560). Robison et al. (2009) concluded that stroke survivors needed to
address the emotional and behavioural responses people made to their stroke in order to adjust positively.

Similarly a systematic review of 95 qualitative studies involving stroke survivors identified an overarching theme of “loss” in life after stroke including loss of activities and identity (McKevitt, Redfern, Mold, & Wolfe, 2004, p.1501). Despite this relatively extensive review, there is no specific mention of the bodily experience of stroke and the authors concluded there was a need for greater participation of health service users in future research (McKevitt et al., 2004) with acknowledgment of how intensely personal the stroke experience is to each individual (Burton, 2000). Greater understanding of the embodied experience of stroke may be an important part of this adjustment process and improve resumption of meaningful activities.

2.4.2 Quality of life

Quality of life is significantly affected following a stroke (Carod-Artal, Egido, González, & De Seijas, 2000) and the embodied experience may play an important part in achieving higher quality of life given that embodiment recognises the lived experiences of stroke survivors. Quality of life is described as the “individuals’ perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns” (The WHOQOL Group, 1998, p.1570). Physical activity influences the physical and mental aspects of quality of life after stroke (Carod-Artal et al., 2000; Chen & Rimmer, 2011) but only in the short
term (Chen & Rimmer, 2011). Similarly, physiotherapy has been suggested as important in enhancing quality of life especially in terms of exercise (Chen & Rimmer, 2011). However long-term quality of life is dependent on factors other than exercise and physical ability, which may be influential for physiotherapeutic approaches, which historically have focused on physical aspects of health in isolation.

Quality of life is not strongly correlated with stroke survivor’s level of physical function indicating that resuming physical ability alone does not necessarily improve quality of life (Carod-Artal et al., 2000; White et al., 2007). White et al. (2007) allude to the need for clinicians to look beyond function when considering long-term quality of life for stroke survivors. Similarly, in a general literature review exploring determinants of health related quality of life after stroke, the predictors identified were disparate (Carod-Artal et al., 2000). Although functional status was identified as a predictor in some studies, depression, stroke type and age were more common predictors. This suggests that it is prudent to look beyond physical function when considering quality of life in stroke survivors.

2.5 Transition to community

This thesis explored the embodied experience of stroke one month after leaving hospital, a substantial transition point in the recovery from stroke. Transition home following a stroke is consistently described by stroke survivors as challenging (Cott et al., 2007; Ellis-Hill et al., 2009; Rittman et al., 2004; Sarre et al., 2013). A transition can be
described as “a passage from one life phase, condition, or status to another and is embedded in the context of a particular social situation” (Rittman et al., 2004, p.260). Transition home for stroke survivors often results in feelings of loss, uncertainty and social isolation (Salter et al., 2008). Transition from hospital has also been described as a period of contradictions in perceived progress, emotions and self, with feelings of “loss of momentum” (p.64), “being abandoned” (p.66), and “being in the dark” (Ellis-Hill et al., 2009, p.68). It is during this transition that stroke survivors may also identify an altered “sense of self” (Rittman et al., 2004, p.264) of which the body is one component. Although these studies do not specifically consider the embodied experience on transitioning from hospital, they suggest that this is often a time stroke survivors reflect on their sense of self, which may relate to their bodily experiences.

Constructions of self are in part gained from bodily experiences (Murray & Harrison, 2004) hence are intimately linked with the embodied experience. Sense of self has been thought to be overlooked in evaluations of stroke rehabilitation and in wider models of rehabilitation such as the International Classification of Functioning and Disability, especially in relation to the transition to the community (Cott et al., 2007). It is this transitional stage which I have been especially interested in exploring as it appears to evoke questioning and quest for meaning in stroke survivors. When stroke survivors leave hospital they begin to revisit their pre-stroke life roles and activities for the first time with their changed, post-stroke body. It is therefore a time of learning and reflection for stroke survivors as they gain understanding of their body in everyday life, and what having a changed body means to them.
Personal, psychological, social and environmental factors help or hinder stroke survivors during the transition process when people adapt to changes in their self, social connectedness and community participation (Gage, Noh, Polatajko, & Kaspar, 1994; Gustafsson & Bootle, 2013; Sarre et al., 2013; Wood et al., 2010). For instance self-efficacy, a person’s belief in their capabilities, is an important aspect of community reintegration in terms of quality of life, and return to meaningful roles (Gage, et al., 1994; Sarre et al., 2013; Wood et al., 2010). Similarly personality, adjustment practices and relationships are important in preserving resilience following stroke (Sarre et al., 2013). Transitioning from hospital has been termed the “modelling phase” (Gustafsson & Bootle, 2013, p.1383) and often reflects a time of evolution from physically focused goals to establishing independence and then finally returning to “real living” (Wood et al., 2010, p.1048). Health professionals and services have been found to influence the success of transitioning from hospital although the mechanisms for this are unclear (Turner et al., 2008). Thus the relationship between personal, psychological, social or environmental factors and embodiment are currently vague, but given their influence on other aspects of the transition experience, they are likely to play a role in the embodied experience. Despite much research focused on transition from hospital after stroke, there is little understanding of the embodied experience (Pringle, Hendry, & McLafferty, 2008).

2.6 Summary

The embodied experience of post-acute stroke, particularly during the transition from hospital to the community, remains elusive in theoretical models of rehabilitation.
Though common themes of the bodily experience of stroke have been identified, the notion of embodiment remains poorly defined and dominated by discourse on the objectively-perceived and physical body. The experience of stroke continues to be compartmentalized as is reflected in the organization of stroke rehabilitation services and research literature. Transition from hospital has been described by stroke survivors as a challenging time and is often associated with reflections of the self, hence is an important time in which to consider capricious experiences of one’s body. This study further explored the embodied experience of stroke one month after leaving hospital. It is hoped that this thesis will add to current knowledge and contribute to future theoretical models so that the embodied experience can be integral to physiotherapy stroke rehabilitation practice.
Chapter 3: Methodology and Methods

3.1 Introduction

A constructivist approach to grounded theory as described by Charmaz (2006) was utilised to develop a theoretical model of embodiment in the transition to life after stroke. Seven interviews were conducted with people over age 65 one month after discharge from hospital following a first stroke. Scientific rigour was promoted through a variety of methods widely accepted in grounded theory. Ethical issues regarding peer review, recruitment and competence were satisfactorily addressed and approval was granted by the relevant ethics committee. This chapter will describe and explain the selected methodology and methods in further detail. First however, in order to understand the rationale for the methodology, I establish my theoretical perspective as a researcher.

3.2 Philosophical and theoretical perspectives

Grounded theory is an established approach to qualitative research. However, dispute exists as to exactly how grounded theory be conducted under particular conditions (Crotty, 1998; Mills, Bonner, & Francis, 2008). Furthermore, a number of differing philosophical and theoretical perspectives exist underpinning what is called grounded theory. This study utilized a constructivist epistemology to grounded theory with a relativist ontology. The theoretical perspective behind this methodology was that of symbolic interactionism. This section serves to explain these terms, describes the
foundations of grounded theory, and justifies why this approach and perspective was endorsed for this particular research question.

3.2.1 Justification for grounded theory

Grounded theory was selected as the specific qualitative research method as it enables generation of research-based knowledge about the behavioural patterns that shape social processes (Glaser & Strauss, 1970). Grounded theory is an approach where conceptual frameworks or theories are developed from information ‘grounded’ in the data. A theory can be defined as a “set of well-developed concepts related through statements of relationship, which together constitute an integrated framework that can be used to explain or predict phenomena” (Strauss & Corbin, 1998, p.15). Theories developed from this method are usually substantive where the contexts are expansive, such as in the experience of stroke. A further rationale for grounded theory for this study is that it serves to explain what is being expressed rather than being based on a priori orientation. This is especially pertinent when researching the notion of embodiment in stroke, where there are currently no widely established theories (Ellis-Hill et al., 2000; Faircloth et al., 2004a; Wilde, 1999). Alternative qualitative approaches such as phenomenology or ethnographic research, although still aimed at gaining a more in-depth understanding of human experience, do not aim to develop theory. Furthermore, grounded theory is underpinned by an inductive approach to data collection whereby the researcher does not set out to either prove or disprove ideas or hypotheses (Mills et al., 2008). Thus grounded theory provides a structured approach to actively position the researcher as the author of a reconstruction of
participant experience and meaning (Charmaz, 2006) with intertwined analysis and theory development (Mills et al., 2008). Therefore grounded theory methodology provides a logical approach for advancing theory of the relatively poorly understood concept of embodiment for stroke survivors.

**History of grounded theory**

Grounded theory has evolved into an established approach with systematic, explicit processes for theory development. It was first developed in the 1960s by Barney Glaser and Anselm Strauss, whilst exploring the experience of dying (Charmaz, 2006). It was during this study that grounded theory methodology began to coalesce, resulting in the documentation of methods for systematically generating new theory from data. This notion of generating theory, while simultaneously collecting and analysing data resonated with other social scientists looking for a more robust approach to qualitative theory development and the approach became increasingly popular (Kennedy & Lingard, 2006). Since this first generation of grounded theorists, a number of subsequent theorists have established their own interpretations and approaches to grounded theory including Corbin, Clarke, and Charmaz (2006). Each of these theorists have taken their own philosophical stance but all have been underpinned by the use of inductive analysis to develop conceptual frameworks or theories (Charmaz, 2006). Grounded theory is also consistently characterized by the fusion of data collection and analysis, shaping of data collection by initial data analysis, and the detailed systematic procedures for data collection, analysis and theorizing. Despite these commonalities, a number of interpretations of grounded theory
exist, each with associated guidelines. Each interpretation differs on a number of fundamental aspects of grounded theory both at philosophical and procedural levels (Mills et al., 2008). Hence when employing grounded theory it is necessary to specify epistemological, ontological and theoretical assumptions.

3.2.2 Relativist ontology

Ontology is the study of being and existence; the beliefs regarding what is reality. A relativist approach assumes that multiple realities exist. This approach is advocated by grounded theorist, Charmaz (2006) who considers the context of participants’ responses, including the social context, as important. This is well suited to exploring individuals’ experiences of embodiment which are likely to be dependent on their unique situation.

Given the complexity of human experience it seems incongruous to presume that there will be only one ‘true’ version or correct interpretation of reality. This view is contrary to that of Glaser and Strauss who took a stance of critical realism which assumed that although an objective reality exists this reality can only be perceived imperfectly (Mills et al., 2008), therefore a ‘real’ or ‘true’ social reality is surmised. Given that every participant has a unique stroke experience and a unique journey to recovery (Cott, 2004) it is unlikely that there will be one single social reality of embodiment in the transition to life after stroke. Therefore a relativist ontology founded the approach to this study of embodiment.
3.2.3 Constructivist epistemology

Epistemology relates to the nature of knowledge and meaning. Whereas ontology relates to beliefs about what constitutes reality, epistemology relates to how we make sense of reality. A constructivist epistemology is a belief that people construct the realities in which they participate and that meaning is not presumed to reside in objects (Crotty, 1998). In Charmaz’s interpretation this means that “both data and analysis are seen as created from shared experiences and relationships with participants” (Charmaz, 2006, p.130). This approach rejects the belief that the researcher can be entirely neutral and objective in their extraction of data and theory development as pioneering grounded theorists advocated (Mills et al., 2008). The stance of Charmaz resonated well with me as a researcher. I was already embedded in my clinical role working with stroke survivors and, as a postgraduate student, I had extensive exposure to research exploring peoples’ experiences following stroke. Therefore my ability to be impartial and objective was contestable. It would have been naïve to assume that I could separate myself entirely from my inner beliefs, preconceptions and approach with this client group. The way I conducted interviews and interpreted data was specific to my construction of meaning. Furthermore, the way in which participants expressed themselves was constructed in their interpretation of their reality at that moment in time and hence knowledge was clearly socially constructed by them also. A constructivist approach recognizes this shared experience and relationship I had with participants when questioning them about embodiment following their stroke.

A constructivist approach is contrary to ‘objectivism’ and ‘subjectivism’ which are alternative epistemological approaches. Objectivism views that objects exist as
meaningful entities with truth being separate from experience and consciousness and sees data as real and independent from the processes of their production (Crotty, 1998). This infers that the researcher is a neutral observer. These notions are not complementary to my research question as the purpose was not to seek ‘one truth’ through neutral observation, but to better understand complex experiences. Conversely, subjectivism views that meaning is imposed onto objects by the researcher, rather than being constructed through the interaction between the subject and the object (Crotty, 1998). Thus subjectivism emphasises the thoughts of the researcher as opposed to the relationship with the real world, as constructionism aspires. In this study I was expressing my understanding of the stroke survivors’ reports of their experiences, and in turn, they were expressing their understanding of their experiences of the world. Therefore, together, the research participants and I co-constructed the knowledge which developed into the findings for this study; a constructivist epistemology.

3.2.4 Symbolic interactionism as theoretical perspective

Theoretical perspective is the philosophical stance underpinning a methodology, providing context for the process involved and a basis for its logic (Crotty, 1998, p.16). Symbolic interactionism is defined by Charmaz (2006) as “a theoretical perspective derived from pragmatism which assumes that people construct selves, society, and reality through interaction” (p.189). This perspective postulates that “meanings arise out of actions, and in turn influence actions” (Charmaz, 2006, p.189). This philosophical position appears appropriate for the exploration of stroke survivors’ experiences where peoples’
Construct of their body is likely to be inextricably linked with their interactions; both internally within themselves and externally in the world. Similarly symbolic interactionism also relates to my understanding as the interviewer of participants’ words and my subsequent analysis of their dialogue, recognizing that theory development will be intimately entwined with my interaction and active quest for meaning. This is an acknowledgement that the way I interviewed participants and how I interpreted what was said, shaped theory development. A symbolic interactionist approach to grounded theory therefore acknowledges that active processes are involved for people to create and mediate meanings of their stroke experience.

Symbolic interactionism is contrary to positivism and post-positivism which is the theoretical perspective that underpinned earlier grounded theorist’s work. Positivism asserts that scientific research serves to discover objective things through neutral observation (Crotty, 1998). Post-positivism questions the absoluteness of positivism including the ability to make neutral observations. However, post-positivism still alleges that there is an objective reality to be observed (Crotty, 1998). The idea of an objective reality is an inappropriate perspective for study of stroke survivor’s experiences which relies on interpretations of events and situations. Conversely Charmaz’s approach to grounded theory underpinned by symbolic interactionism emphasises interpretive understanding of the participants experience with a co-creation of grounded theory (Charmaz, 2006). Therefore the researcher is not considered independent from that which is being researched.
Symbolic interactionism recognizes that the researcher is likely to have undertaken some prior reading around the topic leading to the generation of a research question. Unlike Glaserian grounded theorists, Charmaz does not consider that this prior reading necessarily contaminates the analysis (Bryant & Charmaz, 2007). Instead Charmaz states that “preconceived theoretical concepts may provide starting points for looking at your data but they do not offer automatic codes for analyzing these data” (Charmaz, 2006, p.68).
To compose this research question I had already become familiar with the area of embodiment and transition in stroke survivors through the existing research literature. However, when it came to data analysis I distanced myself from the literature, by not reading any publications during this time, to allow a more inductive approach to analysis to occur whereby theory emerged from the data as opposed to data being a means of theory verification. This process illustrates how these philosophical and theoretical assumptions impacted on methodological decisions and resonated throughout the research process.

3.3 Methods

The methodology process is represented in Figure 1. The concurrent data collection and analysis illustrated is a crucial defining feature of grounded theory.
Sampling
- Training of recruiters working on stroke ward
- Recruiters identify participants and give information sheet
- Purposeful sampling with initial participants.
- Theoretical sampling with later recruits
- Recruiters advise me of potential participants
- Prior to hospital discharge I met with participants
- Informed consent form signed

Data collection
- Participants contacted weekly via phone for first 3 weeks after discharge home
- Phone calls digitally recorded and memos taken
- Interviews undertaken with participants (+/- family member) in own home
- Digital audio-recording of interview taken and transcribed verbatim

- Data analysis
- Initial coding of transcript
- Peer coding 100% of transcripts
- Codes analyzed and developed
- Cross coding between transcripts
- Codes formed into theoretical framework
- Concepts tested and revised on subsequent interviews
- Theoretical sampling until theoretical saturation

Thesis write up
- Comparison of theoretical framework with existing literature
- Summary of study findings sent to participants
- Thesis write up

Figure 1: Application of Grounded Theory (Charmaz, 2006) in this study
3.3.1 Recruitment of participants

Potential participants were identified by two recruiters working on the stroke rehabilitation ward at the Princess Margaret Hospital in Christchurch, New Zealand. Recruiters were full-time physiotherapists who were treating the potential participants and could readily determine if potential participants met the inclusion and exclusion criteria for the study. Recruiters were instructed on the overview of the study (see Appendix 1 for recruiter information sheet) but otherwise had no vested interest in the research project. The recruiters were provided with a resource folder including all the information sheets and inclusion criteria checklist. They approached potential participants and informed them of the study but made it clear that participation was entirely optional and the decision would not influence their care in any way. If potential participants were interested in receiving further information, recruiters provided the participant information sheet (see Appendix 2) and notified me. I then arranged to meet potential participants in person on the ward. At this stage I iterated the content of the information sheet verbally with potential participants and checked their understanding of what was involved if they were to participate. If the potential participant remained interested in the study and met the inclusion criteria then written consent was obtained by all participants at this point.
Inclusion/exclusion criteria

People were eligible to participate in this study if they were in hospital for a first time stroke, and were either over the age of 55 years if they were Māori and Pacific Islanders or over the age of 65 if they were of another ethnicity. The decision to recruit only first-time stroke survivors was made to focus the study more specifically on initial experiences of stroke. The inclusion criteria related to age and ethnicity reflected the admission criteria for the Community Stroke Rehabilitation Service of the Canterbury District Health Board. This criteria is justified because of the disparity for age of onset for stroke which exist between NZ European and Māori or Pacific Island populations (Dyall et al., 2008; Feigin et al., 2006).

Participants also needed to self-identify as having experienced a significant change in physical ability since their stroke. The purpose of this criterion was to focus the study on exploration of the experiences of people with stroke regarding body changes, so if they felt they had experienced no physical changes their experience would not inform this research question substantially. People also needed to have the capacity to consent to participate in the study. Judgement of capacity to consent was made on the basis of functional evaluation of their cognitive abilities. This evaluation was conducted by the recruiting physiotherapist based on their professional expertise and the clinical records to which they had access. Cognition was routinely considered by the recruiting physiotherapists in conjunction with their team as part of discharge planning. Although no formal screen of cognition was conducted for the purposes of this study, the knowledge the recruiting physiotherapists had of the person,
combined with the person’s ability to engage with me during our initial meeting was deemed to provide sufficient functional indication of their ability to consent and participate. People with aphasia were included if cognition was otherwise intact.

Recruiters were advised to exclude people who were medically unwell based on medical team assessment, or lived outside of the Greater Christchurch area. People were excluded who were unable to communicate in English.

*Sampling techniques*

Purposeful sampling was initially used to select the first two participants to allow a starting point from which theory could grow. This is an accepted technique to maximize possibilities of obtaining data by starting with a sample where the phenomenon being researched is known to occur (Coyne, 1997). The criteria described in ‘Inclusion/exclusion criteria’ were the only parameters stipulated to recruiters for the first two participants. Subsequent participants however were selected using theoretical sampling.

Theoretical sampling is particular to grounded theory and is integral to the constant comparative method whereby initial data analysis informs subsequent decisions regarding what data needs to be collected next and from which specific sources (Charmaz, 2006). This meant that I, in collaboration with my supervisors, made strategic decisions about which participants were likely to provide the most information-rich data to meet the analytical needs
of the study. For instance, at one stage people were sought who had experienced severe physical weakness from their stroke. This was achieved through regular discussion with the recruiters and made it necessary to stagger participant recruitment to allow time to develop emergent categories and modify selection criteria accordingly. Recruitment continued until theoretical saturation was reached. Theoretical saturation is “the point at which gathering more data about a theoretical category reveals no new properties nor yields any further insights about the emerging grounded theory” (Charmaz, 2006, p.189). Controversy exists as to whether theoretical saturation can truly ever be reached, or if it is possible to objectively determine when data saturation might be reached (Hallberg, 2006). From a pragmatic perspective however, it has been suggested that theoretical saturation can be considered when collecting further data is counterproductive in that it offers no further explanation to the emergent theory (Mellion & Tovin, 2002). This study adopted the stance to theoretical saturation of Charmaz and stopped recruitment when no new categories were being generated from the data, at which point seven participants had been interviewed.

In my role as physiotherapist with the Community Stroke Rehabilitation Service in Christchurch I would usually work with a number of the participants recruited on their return home. However, to ensure there was no conflict of interest it was arranged that all participants recruited into the study were treated by another physiotherapist in the service. It was made explicit that in my role as researcher I would not be providing any rehabilitation advice to participants and would redirect them to discuss with their health care providers any issues that
arose. Furthermore, all information gained from participants was treated as confidential, although participants were aware their General Practitioner could have been contacted if any concerns around participants’ personal safety arose such as suicidal ideation. Confidentiality was important as it allowed participants to talk openly with me as a researcher rather than a health professional, potentially allowing them to disclose more information whilst aiding them to be at ease. Participants were aware that I was a physiotherapist but no details of my role were provided until after the interview was complete.

3.3.2 Data collection

Basic demographic data of participants was collected by myself from hospital records including age, ethnicity, stroke type, length of hospitalisation, residential status, and functional ability. This information served to provide descriptive and contextual information about the subjects and included;

- Stroke type. This was recorded as either haemorrhage location or using the Oxfordshire Stroke Classification Project system (Bamford et al., 1991) if it was an infarct, which is the standard classification used by the CDHB. This system classifies according to stroke location in the brain, which indicates the nature of stroke impairment (see Table 2).

- Length of hospital stay. This was recorded to provide proxy indication of stroke complexity which may have impacted on participants embodied experience.

- Residential status post discharge. This was captured as being either living alone, living with others, rest home or hospital level care. This provided an indication of the
environment into which participants were transitioning. Note that I am referring to all these discharge destinations as being participants’ home throughout this thesis.

- Functional ability. This was captured via the Barthel Index. The Barthel Index of Activities of Daily Living is a measure of 10 common activities of daily living (Collin, Wade, Davies, & Horne, 1988) which was completed by me based on their hospital records. It is generally accepted as a reliable and valid measure of functional ability for the descriptive purposes of this study (Salter et al., 2005).

Table 2: Oxfordshire Community Stroke Project classification for ischaemic stroke (Bamford et al., 1991)

<table>
<thead>
<tr>
<th>Classification</th>
<th>Presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Anterior Circulatory Infarct</td>
<td>New higher cerebral dysfunction (dysphasia, dyscalculia, visuospatial disorders)</td>
</tr>
<tr>
<td>(TACI)</td>
<td>Homonymous visual field defect</td>
</tr>
<tr>
<td></td>
<td>Ipsilateral motor and/or sensory deficit of at least 2 areas of face, arm and leg</td>
</tr>
<tr>
<td>Lacunar Anterior Circulatory Infarct</td>
<td>Pure motor stroke (most common) OR</td>
</tr>
<tr>
<td>(LACI)</td>
<td>Pure sensory stroke OR</td>
</tr>
<tr>
<td></td>
<td>Combined sensory-motor</td>
</tr>
<tr>
<td>Partial Anterior Circulatory Infarct</td>
<td>Only 2 symptoms of TACI OR</td>
</tr>
<tr>
<td>(PACI)</td>
<td>Higher cerebral dysfunction alone OR</td>
</tr>
<tr>
<td></td>
<td>Motor/sensory deficit more restricted than LACI (eg. Confined to 1 limb)</td>
</tr>
<tr>
<td>Posterior Circulatory Infarct</td>
<td><em>Any of:</em></td>
</tr>
<tr>
<td>(POCI)</td>
<td>Ipsilateral cranial nerve palsy with contralateral motor/sensory deficit</td>
</tr>
<tr>
<td></td>
<td>Bilateral motor/sensory deficit</td>
</tr>
<tr>
<td></td>
<td>Disorder of conjugate eye movement</td>
</tr>
<tr>
<td></td>
<td>Cerebellar dysfunction without ipsilateral long tract deficit</td>
</tr>
<tr>
<td></td>
<td>Isolated homonymous visual field defect</td>
</tr>
</tbody>
</table>

60
Participants were contacted via phone by myself on a weekly basis for the first three weeks of their return home (i.e. three calls per participant prior to the much more extended semi-structured interview). It has been suggested that this type of prolonged engagement with research participants can enhance the depth of relationship between participants and researchers, and therefore enhance the credibility of the research (Charmaz, 2006). From a constructivist epistemology, the richness of the data generated from an interview is dependent in part on the relationships between the researcher and participants. The phone calls were audio-recorded and transcribed. This phone contact was structured with questions focused on an overview of their week, perceptions of physical activity and discussing any observations they had made regarding their body (see Appendix 3 for phone guide). The purpose of these initial phone calls was three-fold: 1) to build rapport with the participant prior to the main interview, 2) to gather information about their initial experiences of their body and attempting to return to physical activity after discharge from hospital, and 3) to provide contextual information about the participants lives to inform the development of the main interview questions. The length of the phone calls was intended to be brief and ranged from 2 minutes 44 seconds to 11 minutes and 11 seconds. On average phone interviews were six minutes. As intended, I perceived that the interviews enhanced rapport and therefore the credibility of this constructivist grounded theory study.

At one month post-discharge a date was agreed with the participants for the completion of the semi-structured interview. This interview was unique for each participant, consisting of
open and non-directive interview questions, but was based on an interview schedule which
centred on the experience that participants had had of their body since their stroke (see
Appendix 4). Questions were initially developed from theoretical concepts alluded to in
existing research. The interviews were conducted at a location of the participants’ choosing
which in all cases was in their own home. This was undertaken so that each interview was held
where participants felt most comfortable and therefore most open to reflection and
conversation. The interviews lasted between 32 and 69 minutes, and were digitally recorded
then later transcribed verbatim. Pseudonyms were used for all participants and any identifying
information (e.g. names of places or organisations) was replaced by non-identifying
descriptive terms to maintain anonymity.

As a novice researcher, developing interviewing skills to facilitate rich data collection
was paramount. I therefore undertook a preparatory practice interview with one of my
relatives to check the flow and content of the interview guide questions. This process
prompted me to further develop the introduction to the interview in order to better prime
participants to the style of interview, plus to develop an exit section to ensure the session was
terminated in a non-abrupt manner. Throughout the data collection process regular
supervision occurred to help enrich my interview skills and to develop successive interviews.
Although all interviews were founded on a single interview guide the line of questioning was
tailored to each participant and evolved as the study progressed in relation to emergent
categories. This evolution of questioning is another feature of theoretical sampling (Charmaz, 2006) and enables theory development which is grounded in the data.

3.3.3 Data analysis

Data analysis followed the constant comparative method of grounded theory. The data, transcribed verbatim by myself (see Appendix 8 for key to transcription conventions), from the semi-structured interviews was exported into qualitative data analysis software NVivo (QSR International Pty Ltd, 2012), where it was manually coded and categorized using the constant comparative method. The relationship between identified codes and categories was explored with increasing levels of abstraction of the data. This involved utilizing initial coding (Charmaz, 2006) which was open, remained close to the data and was completed quickly. Next, focused coding (Charmaz, 2006) was utilized which was more conceptual in nature and involved sifting through codes to find the most significant and frequent codes. At this stage there was much time spent back and forth between each participant’s data to check emergent coding both at the initial and focused level. Finally axial coding (Charmaz, 2006) was employed in which categories were related to subcategories, thus recognizing the interplay of categories. Throughout this process, as well as before and after data collection, I used journaling and memos to document development of ideas. Part of this analysis process required me to move from inductive analysis towards abductive reasoning in which I attempted to consider “all possible theoretical explanations for the data, forming hypotheses for each possible explanation, checking them empirically by examining data, and pursuing the
most plausible explanation” (Charmaz, 2006, p.104). These coding practices were not a linear process but a dynamic process moving between codes and participants. Memos were written throughout all levels of coding on any emerging ideas. All transcripts were peer coded by my supervisors and emerging themes discussed regularly with supervisors. Collectively this process facilitated theories to be constructed rather than discovered (Charmaz, 2006). Use of the constant comparative method meant that there was a fluid interplay between data collection, methodology and analysis with theory development being entwined throughout.

3.3.4 Scientific rigour

Standards for rigour have been accepted by grounded theorists to increase trustworthiness of findings however processes vary between theorists. For this study the processes advocated by Charmaz (2006) were used. Charmaz (2006) advocates for the criteria of credibility, originality, resonance, and usefulness – all underpinned by reflexivity to enhance trustworthiness. These elements recognize that there is interpretation and subjectivity involved in grounded theory and therefore serve to promote transparency throughout to enhance rigour.

**Reflexivity**

Reflexivity can be considered as a scrutiny and transparency which the researcher provides (Hall & Callery, 2001). Transparency in my preconceptions as a researcher, was
promoted through the widely accepted strategies of journaling, memo writing, audit trail through NVivo (QSR International Pty Ltd, 2012) software, peer debriefing and engaging in reflexive self-awareness. A presuppositions interview with an independent, experienced scholar was undertaken to facilitate this reflexive self-awareness. The interviewer prompted self-reflection on being both a researcher and a practitioner and the potential impact this might have on how I questioned participants and interpreted their words. Furthermore it compelled me to consider the potential dilemmas for participants seeking professional advice from me and the potential impact of emotion evoking interviews on participants. At times participants were asked to discuss sensitive feelings and issues. As a healthcare practitioner it was counterintuitive not to validate or respond to these experiences as I felt conditioned to address these issues through rehabilitation input. However, through debriefing and journaling I developed my skills as an empathetic listener and structured the interview in such a way to allow natural closure. Reflexive preparations for interviewing also crystallized for me the need to allow participants to talk tangentially from my questions in order to express more deeply held reflections. My insights described here have been echoed by other authors undertaking research as a clinician (Conneeley, 2002).

Credibility

Credibility refers to whether there is sufficient evidence to support the claims made (Charmaz, 2006). It relates to how believable reported findings are regarding the phenomenon under discussion. Methods for enhancing credibility that were used in this study included;
• Allowing participants to guide the enquiry process through open questioning and exploring statements they made.

• Checking generated theoretical construction against participants’ meanings of the phenomenon by directing questioning to subsequent participants.

• Using participants’ actual words in the theory. Similarly using extended extracts from the interviews to illustrate that the proposed theory was in fact grounded in participants’ statements.

• Articulating my personal views and insights regarding the phenomenon explored. This included writing memos to document emerging ideas, log booking and regular supervision sessions to discuss emerging ideas and explore the way in which prior knowledge may be imposing on the data. This promoted systematic comparisons and a clear attendance to the process of theory construction every step of the way.

• Peer coding where data was coded independently by me and then independently coded by my supervisors. This was so data could be checked for clear emergent themes and to enrich the analysis process.

Originality

Originality refers to whether categories provide new insight (Charmaz, 2006). This involved reviewing existing literature surrounding stroke, embodiment and transition to both provide a theoretical frame of reference and to establish gaps in understanding. As already highlighted controversy exists around the place of the literature review in grounded theory
research. Consistent with Charmaz’s stance, some reading was undertaken prior to data collection, and then a more focused and in-depth review of the literature was undertaken after categories and theories had emerged. A “theoretical agnosticism” (Henwood & Pidgeon, 2003, p.138) was attempted whereby I took a critical stance towards earlier theories. This confirmed that the emergent theory was able to provide new insights into the area of embodiment in the transition to life after stroke, and minimized the chance of re-discovering and re-labelling previously established ideas and theories.

Resonance

Resonance refers to whether the categories portray the fullness of the studied experience (Charmaz, 2006). This was again achieved through the process of theoretical sampling whereby progressive interviews were targeted to enhance or reject an emergent category. Furthermore, open questioning ensured participants were able to freely express their experience. Resonance was further enhanced by member checking through sending a summary of findings to participants and allowing opportunity for them to respond. See Appendix 5 for the summary of findings provided to participants. No objections were made by participants and the feedback received stated “I have learnt to slow down and take each day as it comes” and “I have to remember it’s what I can do, not what I used to do”.

67
Usefulness

Usefulness refers to whether the theory offers interpretations that people can use in their everyday worlds (Charmaz, 2006). This was challenging to judge until research findings were formally disseminated. However during presentations of preliminary findings to colleagues, the topic resonated with their practice from questions, discussions and informal feedback received. For me, this research question was deeply entwined with the role that I worked in at the time, and emerged from a lack of understanding regarding embodiment in stroke. Therefore to me this study is directly relevant for the people who deliver services such as the Community Stroke Rehabilitation Service. Similarly participants expressed in interviews a strong desire to share their experiences in order to help other stroke survivors, suggesting they too placed value on better understanding the experience of stroke. Knowledge in this area of embodiment post-stroke serves to enhance current understanding, but also serves as a platform from which further knowledge can grow.

3.4 Ethical and cultural considerations

The research received ethical approval from University of Otago Human Ethics Committee (Health) on 6th September 2013 (Reference: H13/060, see Appendix 6). The Committee requested clarification on the level of peer review, recruitment process, and assessment of cognitive competence of participants. Peer review was provided by the Rehabilitation Board of Studies (University of Otago) at the time the research proposal was developed. Ongoing supervisory support was provided from Dr Fiona Graham and Dr
William Levack. The recruitment process and evaluation of intact cognition/competence was also clarified as per section 3.3.1.

The research received an endorsement from Ngai Tahu Research Consultation Committee on 23rd July 2013 (see Appendix 7). The committee suggested that ethnicity data be collected, and liaison with the Māori Research Advisor at the University of Otago, Christchurch. Both of these suggestions were implemented.
Chapter 4: Results

4.1 Introduction

Eight people were approached to participate in the study over a period of three months. One individual in the post-discharge phase of the study decided against participating when he was contacted by phone. Therefore a total of seven participants were interviewed ranging in age from 66 to 89 years old, five being men, and two being women, all of New Zealand European ethnicity. Participants’ stroke type, length of admission and circumstances varied and are summarized in Table 3. Two participants chose to have their spouse present during the interview, both of whom contributed minimally to the conversation and spousal input was not coded. To maintain confidentiality descriptive information has been kept to a minimum and each participant has been given a pseudonym.
Table 3: Overview of participants

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Stroke type(^3)</th>
<th>Length of hospital stay (weeks)</th>
<th>Residential status at time of interview</th>
<th>Barthel Index on hospital discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Matthew</td>
<td>79</td>
<td>Right posterior circulatory infarct</td>
<td>4</td>
<td>Alone in own home</td>
<td>95/100 (mild)</td>
</tr>
<tr>
<td>George</td>
<td>84</td>
<td>Left posterior circulatory infarct</td>
<td>7</td>
<td>With wife in own home</td>
<td>95/100 (mild)</td>
</tr>
<tr>
<td>Grace</td>
<td>89</td>
<td>Right partial anterior circulatory infarct</td>
<td>12</td>
<td>Private hospital facility</td>
<td>30/100 (severe)</td>
</tr>
<tr>
<td>Helena</td>
<td>78</td>
<td>Right partial anterior circulatory infarct</td>
<td>6</td>
<td>With daughter in own home</td>
<td>80/100 (mild)</td>
</tr>
<tr>
<td>Peter</td>
<td>69</td>
<td>Right posterior circulatory infarct</td>
<td>6</td>
<td>Alone in own home</td>
<td>95/100 (mild)</td>
</tr>
<tr>
<td>Michael</td>
<td>66</td>
<td>Right lacunar circulatory infarct</td>
<td>10</td>
<td>With wife in own home</td>
<td>65/100 (moderate)</td>
</tr>
<tr>
<td>Don</td>
<td>79</td>
<td>Left total anterior circulatory infarct</td>
<td>4</td>
<td>With wife in own home</td>
<td>25/100 (severe)</td>
</tr>
</tbody>
</table>

\(^3\) Oxfordshire Classification (Bamford et al., 1991)
4.2 Overview of theoretical model

The core experience of the embodied self after stroke for participants one month following discharge from hospital was being in a state of flux between having a ‘divergent body-self’, that is ‘this body and me’, through to having a ‘cohesive body-self’, where there was a sense that ‘it’s all me’, illustrated in Figure 2. Flux refers to the flowing and movement of emphasis and awareness that occurred between these concepts. The ‘cohesive body-self’ was related to a sense of control and freedom, both literally in terms of the control of one’s body, but also more abstractly in relation to personal agency such as independence and control over decisions. The ‘cohesive body-self’ also related to an individual’s sense of identity which, for some, remained a constant, and for others, was redefined. Conversely, a ‘divergent body-self’ whereby participants described their body being disjointed from their personhood, was associated with a sense of bodily strangeness and a body which was both unpredictable and effortful. The ‘divergent’ and ‘cohesive’ body-selves, though opposing conceptually, were not mutually exclusive, and can therefore be considered as orthogonal. Orthogonal means having a set of mutually perpendicular axes, so that people could experience concurrently high or low divergence or cohesion in their body. Thus divergence and cohesion did not sit at opposite ends of a spectrum, but instead were states which participants fluxed between both throughout the interview process, but also gradually over time. Similarly these ‘states’ were not necessarily polar emotionally. Although there was a tendency for the ‘cohesive body-self’ to be referred to positively, the ‘divergent body-self’ could, at times be referenced in a comfortable and positive light also. This state of flux was especially apparent through
contradictions participants made within interviews regarding their sense of having a different body, yet feeling a familiar sense of self, as will be demonstrated later in this chapter.

Participants described a range of factors that appeared to ground and thus reassuringly ‘anchor’ them within what was often a confusing and surreal experience. ‘Anchors’ included the individual’s knowledge, attitude and their environment both social and physical. These factors anchored participants to a more real and coherent bodily experience. These themes and sub-themes are more fully described and explained in the following sections.
Figure 2: Theoretical representation of the embodied experience for stroke survivors transitioning from hospital
4.3 A Divergent body-self

The post-stroke body was frequently viewed as separate to the participant’s sense of self, represented by the theme, a ‘divergent body-self’. This theme encapsulates how participants identified a body which felt distant, and profoundly different from their sense of self. Consequently there was a disruption to the continuity of the participants’ sense of ‘me’ from pre- to post-stroke, with their bodies having become viewed as foreign and separate. Within this theme, participants described a body which was strange, unpredictable and effortful. Bodily strangeness included objectification of the body, a sense of an unreal experience, or simply a body which felt strange. The unpredictable body encompassed both a lack of bodily control and a body which could not be predicted, usually due to fatigue and uncontrolled movement. The effortful body included the struggle of bodily movement, a body which demanded concentration and a body which was slow to act, or follow the participant’s will. Many participants described moments of familiarity with their strange, unpredictable and effortful bodies. However, this was not a static or linear experience. Instead, the experience of a divergent body-self would fluctuate back and forth between a more familiar and united body-self; the ‘cohesive body-self’. This section describes and explains participants’ experiences of having a ‘divergent body-self’ following stroke.

4.3.1 Bodily strangeness

A common view expressed by participants was that their post-stroke body was not only different but strange to them. Strangeness was experienced by all participants despite
a broad range of stroke types and physical effects from their strokes. Participants would state simply how “it’s just strange” (Michael). The experience of strangeness was challenging for some participants to explain and was often associated with frustration, but also at times, with curiosity. For instance Peter reported a profound strangeness when he tried to explain the weakness in his left leg:

Oh, I don’t know how to describe it really. It won’t do what you want it to do most times, you know. You want it to, it’s a strange feeling to have it not connecting with your brain. And you take it as, when you’re normal, that’s not there when you’re normal. How can I say it? You don’t think anything about it. When you’re wanting to try and do something, and it won’t let you do it. It’s the strangest feeling in the world.

Here Peter identified the strangeness of his leg “not connecting” with his brain but yet emphasized the inexplicability of the strangeness. He also highlighted how, prior to the stroke, he had not ever thought about how his body felt connected – it was simply “normal”. The stroke however had caused a disconnection between what he was asking of his body and what it did, creating strangeness of his own body.

Altered sensations

Some participants were able to isolate a specific reason why their body felt strange to them. One reason was that their bodies produced physically new or different sensations than they had previously experienced. For instance when Peter was asked if his strangeness was lessening as he was getting stronger (10 weeks after his stroke) he stated;

I don’t think so. It’s still, I’ve still got that, no I don’t think so. It’s still feeling very strange to me. Very strange to me. It’s always cold, my foot’s always
cold. I feel like I’m grizzling but I’m not really. I don’t know how to answer that really, to be quite frank with you.

The inexplicability of the strangeness prevailed. Peter divided himself from his body which felt strange stating “very strange to me” rather than ‘I feel strange’. This statement infers he did not feel strange in his sense of self, just in his body. Peter did attempt to qualify his statement by describing altered sensation, although he suggested, that like the disconnection between his mind and body, the altered sensation is just one component of the strangeness. However, other participants attributed their bodily strangeness specifically to altered sensations such as changed spatial awareness or visual changes. Altered sensations were quite subtle for some but yet still perceptible. For instance, George, who had had a posterior circulatory infarct, had quite minor sensory changes but still identified a difference in sensation before and after his stroke that was significant to him;

Well they’ve done a lot of tests on me, with pin pricking and that sort of thing on both legs and really the difference is very minute. It’s not very much at all. I would know the difference but just [participant’s emphasis] know the difference. So if I’m walking I might throw one foot a little bit off centre compared to another one. But very very little. Not as though I was gonna put a foot out and throw it like that or anything [indicates wide step]. I might just put it out and it be a little bit off centre.

George’s change in sensation was not objectively measurable but was perceivable by him and impacted on his familiarity with his body’s movement. In contrast to this subtle change being obviously perceived by George, Matthew had an obvious sensory change which he almost forgot about. Matthew had a left homonymous hemianopia which meant he had lost the vision in the left side of both eyes. He described his experience of having a hemianopia as being a strange feeling;
Oh it’s just…see I’m looking here now and everything looks normal, even with this being blank out here [indicates left side]...Sort of a strange feeling really. Why can’t I, you know, reach out? You know I look over there and I think oh yeah, everything’s normal. But I realize I’m turning my head, I’m not looking out of the [left] side of my eye.

For Matthew, he still felt what he was seeing was the same as prior to the stroke, and had to consciously remind himself of this bodily change which was a strange experience for him. However, Matthew did not express frustration at this strangeness, instead, this was more simply an observation for him. So despite the high impact of his sensory change, Matthew gave little attention to the change in his body. Whilst Matthew was quite accepting of this change, George’s narrative suggested a feeling of shock and heightened response as he described an incidence of recognizing different sensations to what he had been expecting.

When one day I picked up, er put my hand in hot water or something and picked something up, it was just like electricity running through my right hand which is my good one [unaffected arm]. Like electricity. I had to put it down so quick, cos I was going to drop it. I’ll never be game to do it again.

This sensory reaction could be considered as minor at an impairment level (World Health Organization, 2001), and yet George had a heightened response, like electricity, that he had not been expecting and which impacted on George’s day to day life. He responded to this negative bodily experience by making a conscious decision not to undertake that activity again. Thus at times this bodily strangeness was simply an observation, whereas at other times it served as a learning experience, such as George learning not to touch hot objects with his right hand, or Matthew learning to turn his head. In this sense, the strangeness had become familiar.
Objectification

A specific type of bodily strangeness which occurred for all participants to varying degrees was an objectification of their own body. Although objectifying the body is not unique to stroke survivors, the extent that participants did this was profound. Participants often talked about a body which was separate to them, referring to their body in the third person. For instance Grace, who had weakness in her left arm, consistently referred to her arm as ‘it’ as she talked about the experience of trying to lift her arm;

See sometimes in the morning I play with this [referring to arm] and make it come up [lifts arm] and at some points it hurts, but it is, my son is pleased to see me doing this with it. See I lift this now...[attempts to lift arm]...I’m disappointed in it [referring to arm].

Grace’s reference to her arm indicated a sense of her body being separate to herself with Grace being an almost distant operator of her own arm. Her comment that she was disappointed in ‘it’ reinforced this separation from her arm which she had personified and felt negatively about. Similarly Helena spoke of how her left side ‘disobeyed’ her, and again objectified her body as ‘other’, referring to her limbs with the definitive article ‘the’ or ‘it’, rather than the more typical possessive ‘my’;

….the left side um definitely felt as if it wasn’t there, you know. It was um, something you didn’t think about because it wasn’t, the foot wasn’t obeying your mind, your directions. The arm wasn’t obeying directions.

Like Grace, the way Helena spoke about her own arm suggested a separation or distance between her body and mind, with disobedience being suggested when she said “the arm wasn’t obeying directions”. Although Helena consistently objectified her body, she used the generic pronoun ‘your’ when referring to her mind, suggesting a separation
between her body and mind. This idea of dualism in body and mind was also expressed by Don, who had no use of his right arm after his stroke:

*If we talk a bit more about your right arm; as you’re holding it now, what does it feel like?* It’s not very friendly. Not going. I feel it all the way.

Don personified his arm with reference to it as “unfriendly” whilst conjuring an image of a dichotomised personhood. Don expressed an acrimonious relationship, with the stroke-affected body being viewed as hostile. Examples like this, where the participants’ perceived parts of their bodies to be so separate from themselves as to be attributed with distinct opinions and intentions, highlights the extent of the experience of bodily distance and strangeness after stroke. The distance and strangeness was also represented by the use of similes associated with frustration. For example, Michael’s description of his stroke-affected arm;

It was just like a **lump of meat, a heavy lump of meat**. You know you just couldn’t move it; it dangled down. Oh, sometimes it’d get in the road. It was no bloody use at all, especially if you were trying to get dressed.

Like other participants, Michael was frustrated by the inconvenience of his impaired arm on his ability to do tasks like getting dressed. Michael’s description of his arm feeling “like a lump of meat” suggested not only a passivity in his arm, but also a deadness. Phrases such as “a lump of meat” were also used by other participants to express distaste and rejection of their own body. Specifically, George also referred to his body as “meat” when describing a significant fall he had whilst in hospital;

Well what actually happened was that, it was probably my fault, but I’m sure they told me I could go to the toilet if I wanted to. But I was going out to the door in the ward, and I go very much to the left, and I banged into the door,
those smoke doors which are like concrete and I banged my head and my shoulder and I finished up on the floor. Banged my head again, cracked a rib, twisted my neck, hurt my behind down at the bottom; it’s still a bit sore, not bad. What else? Must have been something else (laughs)…I done the lot, yeh. A real box of meat.

The way George described his body as a “real box of meat” suggests a depersonalization of his own body as his body is reduced to an extinguished, lifeless substance. The image of his body being a piece of meat also reinforces the notion of objectification and strangeness about his own body. George went on to explain how this fall “put him back” in his rehabilitation as his body healed. Thus there was a mismatch between the “meat” of his body, a sort of underperforming, disrespected servant, and his own drive to improve, indicated by his attempt to walk to the toilet unsupervised.

Similarly, Peter used a derogatory simile to represent the image he had of himself when he was walking; “Oh, like a loose unit, yeh. Not a very good image, no, not really a very good image”. Peter’s word choice of “not a very good image” again conveys a negative, whilst “a loose unit” pertains to unpredictability, and perceiving himself as being unlike others. Peter’s perception had been reinforced by the physiotherapist in hospital when demonstrating to Peter how he walked.

[The hospital physiotherapist] thought I was walking a lot better, when I went up there [to visit hospital]. But she still felt that, she still described it as, showed me the way I was walking, and I didn’t like that at all (laughs). Is that really what I look like?
For all participants the incidence of stroke marked a profound line between their embodied experience before and after the event, described by several participants as being so marked as to be ‘otherworldly’. George expressed this distinction as like the start of a new book:

Well I said to my daughter, if I was a writer I’d write a book for before the stroke and one for after the stroke. Because I said they’re going to be two worlds that are going to be absolutely different, so different.

Although participants like George were clear in stating that life was different after stroke, it was challenging for participants to express exactly what was different in relation to their embodied experience. Indeed participants often spoke of how “unreal” their bodily experience had been. For instance, when asked what it felt like when she was moving, Grace stated “it’s unreal”. She returned to this word “unreal” often and talked of struggling to work out what was a dream she had had when sleeping and what was real;

Do you think of the image you have of yourself and your body that you have in your mind, do you think that’s changed from before the stroke to now? Oh it’s bound to have, but I can’t think how; I can’t give you any specifics. And it’s taking me a while to sort of separate the imagination from the real. And you know those dreams I was having, I never knew if they were real or fantasy.

Although Grace felt there must have been a changed image of her body, she was unable to explain it. Despite this uncertainty between reality and dreams, when Grace talked about the image of her recovering brain, she expressed that it was “real”;

You’ve talked a bit Grace about your brain and the connections that you’re visualizing. Do you have any images in your mind of the connection of your brain to your body? Yes, that’s what I was saying about those little threads and the pictures, and there was just so many of them. And, well not so many,
just they were so very vital. And you could see them trembling there just waiting to make a connection. But they couldn’t, they couldn’t, there were just too many, or not enough connections, or whatever. You know it was sort of a feeling I could feel. Something was really real.

Grace, like other participants, had an understanding of what was occurring in her body on a neurological level which appeared to assist her in making sense of the strange experience she was having of her body. Her description of the very “real” experience of her nerve endings “trembling there just waiting” is vivid and powerful. This is in contrast to her “blurred” and “unreal” description of her lived experience, with confusion about what was real and what was unreal being echoed in her descriptions of early experiences in hospital after stroke; “I don’t know, the rest of it is sort of blurred to me cos the next thing I knew I was being offered a bed in the [rehabilitation hospital]”.

This notion of an unreal experience is mirrored by George who stated “I didn’t think I was that ill. But then I was in another world. I presume. I don’t know”. Like many participants, Grace and George referred to the early stages after stroke as being a “blur” and struggled to recall events in the initial phases after the stroke, including how they experienced their body. The metaphor “in another world” seems to have been used by George to express an inexplicable experience. Grace and George’s statements also highlight the ontological aspect of the physical experience of stroke with participants questioning their very being and existence. For instance, Grace stated in the interview that “it’s a whole new ballgame” when explaining the changes in her life after her stroke. Like George’s metaphor of life after stroke being like “a new book”, Grace’s expression
suggested not only the profound change that the stroke had induced, but a change in what existence meant for Grace.

In summary, bodily strangeness encompassed a number of facets. Strangeness could be subtle or obvious, and not necessarily directly related to the severity of physical changes. Many participants objectified the affected parts of their body and at times even imposed critical judgment on these parts as being disobedient, lazy and passive, with these body discourses conveying mostly negative images. However, the strangeness of their own bodies was often inexplicable with many participants describing it simply as unreal or otherworldly.

4.3.2 An Unpredictable Body

The participants’ experiences of a ‘divergent body-self” were also apparent in the references they made to a post-stroke body which was unpredictable. This was both in terms of a lack of movement control and of being unable to rely on their body, especially in moments of tiredness. This unpredictability impacted on the embodied experience by changing how participants viewed their body and the control they had, or the lack of control, over their actions. Helena who had dyspraxia as a result of her stroke, described how her arm had become “unpredictable”, as if it had a life of its own;

My arm is [slaps left arm], I can still feel it, I can feel it, but it’s gone unpredictable. It doesn’t, it isn’t doing this so much [demonstrates wavering left arm]; it was knocking the food off my plate or some of it. And yesterday, what did it do yesterday? Something unpredictable.
Helena spoke about her arm as if it were a separate being; one capable of generating its own behaviour. Unpredictability in the body thus overlapped with objectification and bodily strangeness. Helena’s tone reflected being irritated by her arm’s apparent insolence as she attempted to eat her dinner. Furthermore there was an implication that this part of her body could not be trusted due to its unpredictability. The divergence between her body and self was further pronounced by the consistent reference to her arm as ‘it’. This suggested that her arm had taken on its own unpredictable identity.

**Being careful**

An unpredictable body for many participants related to an experience of a lack of control over bodily movements. This caused participants to be more cautious in activities such as walking. For example, Matthew, who had experienced a fall due to his stroke said “you know I’m very careful I don’t trip over. I’m watching where I’m going, and watchful sort of thing” when asked what it felt like for him to walk. Walking, something which usually is assumed as predictable and easy, had become something which demanded caution for Matthew. As a result he had become hyper-vigilant and adopted a role of being “watchful” when walking. Similarly George spoke of his caution when walking;

Well I’m just very careful…I had this bad habit of going left. If I was walking with this here [points to walking frame], sometimes if I got off balance I was likely to be way out here and not leaning way over like that, you know [indicates leaning left, then straight].

George used the past tense to talk about his lack of control in walking suggesting this was not such an issue to him at the time of interview. However, his use of present
tense for “I’m just very careful” implied that he continued to exert caution when walking. The way that George used the word “habit” suggested that although his walking “going left” was not perhaps expected, he had learnt to anticipate this unpredictability. Consequently the unpredictable had become predictable for him, with the outcome of him being cautious.

The caution reported by Matthew and George appeared to enable them to do seemingly risky activities such as bending over and walking. I asked Matthew what he meant by “being careful” to which he replied;

Well, I go out to get the paper, I’ll be tearing down; not tearing down, but I’ll be getting down the drive pretty good...And then when I’m getting the [newspaper], when I am getting along, you’re going too fast, you know. And I’ll deliberately slow down, so I am getting the message, don’t worry about that.

This deliberate slowing down suggested that Matthew, like George, had learnt strategies to resume control over his body, despite his body remaining unpredictable at times. This had enabled him to get the newspaper from the mailbox without falling like he had previously, although these new strategies did require ongoing additional effort to be maintained. This suggests that the embodied experience of the body being predictable versus unpredictable was a dynamic process, requiring regular, continuous attention.

**Tiredness**

Another common issue which impacted on participants’ body predictability was tiredness. This tiredness could lead to participants being surprised by what their body
would do when they were undertaking everyday activities such as walking or shopping.

Michael described what tiredness after stroke felt like;

> Ooh, heaviness in the eyes and the struggle of the brain to work, you know, efficiently and as brightly. You struggle along. There’s certain things where you can get fogged up with your brain when you’re stressed, I’m not referring to that. But just a, your eyes are tending to be heavy and things like that.

This tiredness, which had been unpredictable for Michael in hospital, had become something familiar to him after several weeks at home. Michael was able to recognize the signs of tiredness and differentiate these from other feelings like stress that he was familiar with. Like other participants, he had learnt to predict the unpredictable in his body. In contrast, Peter suggested that the pattern of his tiredness was not predictable from one day to another;

> And the tiredness. I get very tired. I’m quite tired today, whereas yesterday I was fine and the day before. But today I’ve got down to a level where I’m quite tired. Nothing mentally but just tired, the body’s just tired. And I thought well today I’ll just have a quiet day, sit back. And that’s been a big thing for me. Mentally I’m alright, and going to, you know I’ve accepted the fact that this is what, this has happened, this is what’s happened. And um, so be it.

Peter’s comment that “the body’s just tired” suggested a sense of a divergent body to what he considered himself. This sense of divergence was further emphasized by Peter’s division of which experiences he considered to be “mental” versus those he considered to be his “body”. Despite these bodily changes which Peter was unable to predict, he alluded to acquiring a tolerance of this post-stroke embodied experience, indicated by his statement “so be it”.
Thus the divergent body-self is also related to the unpredictability of the post-stroke body. This unpredictable body included both a lack of control and a particular type of tiredness which participants were often surprised by. For some, they had familiarized themselves with this new unpredictability and been able to put in strategies such as taking time to be more careful and recognizing unpredictability in their body to help predict how their body may behave in other situations. For others though, their body remained out of control and unfamiliar; unpredictable.

4.3.3 An Effortful Body

Participants described their post-stroke body as effortful to move and demanding of their concentration. This effort contributed to participants feeling distant from their body after stroke. Participants frequently spoke of the effort their body now demanded to do previously simple tasks. For instance Don, who was unable to move his right arm and had limited movement in his leg described what it felt like to try to move: “It feels different effort [sic]. Effort’s different. But I hope to get it better. But it is slowly coming back”. Don who had dysarthria (slurred speech) and dyphasia (difficulty to speak) as a result of his stroke, clearly expressed the effort that movement now required. Despite this feeling of bodily difference with associated effort, Don remained hopeful for improvement. He also suggested that there had already been a change in the degree that his body was effortful, again indicating this was not a constant experience of effort.
Struggle to move

Effort was often described as difficulty or a struggle to move. For instance Grace described her complete lack of movement in her affected arm when trying to remove her hand from the walking frame; “…this left one, if I get on there [indicates walking frame] it’s so hard to get it off, I can’t seem to move the fingers off. I’ve got to physically shift them”. Grace had to use her unaffected arm to compensate for the lack of movement in her other arm. The expression “so hard” suggested the effort of moving her fingers which were referred to in the third person. When asked what it felt like to move her arm Grace replied “heavy, just heavy as lead. I pick this one up [moves affected arm] and I can hardly lift it”.

Effort was not just isolated to participants like Don and Grace who had little ability to move without help. Other participants, who had more ability to move, also described the effort of walking. For example, Michael spoke of what it felt like to walk;

When I’m walking now it’s quite a bit more effort because you gotta work with each leg to move forward, and you know, make them, place them in the right position and everything like that. So you’re not going to fall or anything like that. Even at this time I’m still using the walking stick.

Despite Michael being able to function to a much higher level than Grace and Don, by for example walking and working, he still experienced effort of movement. This was also despite Michael having made gains in his ability to walk after his stroke, suggesting that skill acquisition or improved strength do not necessarily mean reduced effort.
The ‘struggle’ of an effortful body was not a static experience. The participants’ experience of effort could change within different situations and this was illustrated by the contradictions that were present in participants’ discourse. For example Peter contradicted himself when describing the effort required to move his legs: “I could lift the right leg up, you know from the knee, right up, and the left was flat. Both are the same now, just a bit different”. This indicates his perception of his body having changed, yet the experience of his body was still variable. Peter inferred that the sense of bodily struggle fluxed with the passing of time. For others the perception of struggle was almost lessened by a sense of hope for the future. For example, Michael spoke of being at a “transitional stage”;

*So when you’re trying to do things like trying to put your socks on, and your left arm isn’t able to help you, what does that make you think about your body?*  
Oh, it’s something that you can’t do, and er I think really that you find that you’re wanting to do it, and you will do it. But you’re going through a transitional stage when you can’t do it.

Despite Michael experiencing the struggle of his effortful body at the time of interviewing, he viewed this as a “transitional stage” and anticipated that this effort would subside. The notion of a transitional stage seemed to make the effort of bodily movement more acceptable for participants. For instance Don described his inability to move as “a vertical climb” which depicted both effort and the sense he was on a journey when I asked;

*Don, if you and I were to change bodies now, can you tell me what would I need to know about your body?*  
I can’t move. (Undistinguishable words) It’s a vertical climb, my body.

*What do you mean by ‘vertical climb’?*  
Because I’m way down low, you can’t move, you can’t touch anything, you know your body’s a (undistinguishable words), it won’t move. But slowly [indicates going upwards], I hope.
Don was devoid of any movement in his right arm; it simply “won’t move” he said. This analogy of being low down on a vertical climb suggested both the effort of movement but also the anticipated journey ahead for Don on his recovery for which he was very hopeful.

Concentration

In addition to feeling a struggle to move, participants described the effort of being more aware of their body and having to concentrate on things they had previously performed automatically. For instance, Peter expressed a heightened awareness of his body through considerable mental effort when walking:

My left leg; I’m trying to get it going like my right one. I think I, I um, when I put my right leg forward I have to think, right now I’m going to put my left leg forward the same. But that just doesn’t happen, no. It’s just not gonna happen at the moment. But I don’t, I’m just very very focused on getting that movement, trying to get that movement in my left leg.

Peter had to consciously focus on each individual component of walking, breaking the task down. He highlighted the contrast between his left and right leg indicating the effort of intentionally stepping his stroke affected leg. When asked whether this “focus” changed for him in different situations he responded:

Nah, I think about it all the time to get that movement, try and keep that movement right. Um, I’ve found a good way to get into my car. Rather than try and get in and drag my knee forward, mumble and grumble; I’m very conscious of it. Very conscious of it, to get it right.

Peter had to be conscious of his body at all times to successfully negotiate his environment, presumably unlike prior to his stroke. This concentration appeared quite
consuming for Peter in the way that he said “I think about it all the time”. Similarly Helena, who had a dampened sensory awareness of her body due to reduced proprioception, reported having to be “aware” of her body. This caused her to give more attention to her body within the surrounding environment than she had prior to her stroke.

It feels, it’s just strange. I have to be more aware of this side of me anyway [indicates left side], I have to think about it, this side of me… Well you have to be, spatially you’ve got to be aware. Not banging into things on that side [indicates left], you’ve got to watch how much space you’ve got on that side of you all the time.

Helena recognized that she had become more aware of her left side but when questioned how she increased her awareness she simply said “I don’t know”. This suggested that although a cognitive process was occurring, and greater cognitive effort was required, this had not necessarily occurred at a conscious level. Conversely, Michael described the conscious effort which he had learnt to give his since his stroke;

It’s just a matter of you’ve got to concentrate on what you’re doing. You know before you’d go to walk somewhere or do anything, you didn’t have to think about it. Now, especially when you’re walking, you’ve got to concentrate carefully on it. If you don’t concentrate you can lose your balance and things like that.

Michael’s effort and the concentration required to move his body inferred that whilst the participants’ post-stroke bodies demanded more focus, there was a way to learn how to control their effortful body. In this way the once strange body becomes familiar, the unpredictable body becomes predictable, and the effortful body becomes easier.

All these experiences shaped the embodied experience of stroke. The divergent body-self is epitomized by the distancing participants felt from their bodies. However, this
distance was changeable and the sense of divergence varied in prominence for participants, suggesting the fluxing of the divergent body-self with a more cohesive experience.

### 4.4 Cohesive body-self

In contrast to experiences of a ‘divergent body-self”, an overarching sense of wholeness remained for participants albeit to varying degrees. When expressed, wholeness conveyed participant’s body and self as seamless; a ‘cohesive body-self” which encompassed a sense that the collective experience is ‘all me’. The experience of a ‘cohesive body-self” related to the regaining of bodily control, a feeling of freedom, and a clear sense of identity. For the participants, the experience of regaining control of their body was associated with a sense of progress. Similarly, a number of participants spoke of a feeling of freedom, either present prior to their stroke, or something they had felt again since their stroke. Freedom was referenced both in terms of freedom of movement and in relation to independence. Furthermore, the ‘cohesive body-self” was associated with a clearer sense of identity which prevailed despite many participants being unable to execute the activities which had shaped their previously held self-identity such as being ‘an active person’. These sub-themes of a ‘cohesive body-self” will be further explained in the following section.

#### 4.4.1 Control

Control refers to the participants’ experience of bodily control and their sense of control in their lives generally. All participants expressed how their stroke had influenced
their sense of control, such as Grace who stated “I was completely out of control” when describing her experience in hospital. When participants referred to their sense of control, either over their body or more generally over their lives, they used phrases that reflected a sense of wholeness.

**Bodily control**

Participants’ often experienced a loss of control over their post-stroke bodies as described in ‘the unpredictable body’. Unlike the references participants made to their unpredictable body though, when participants referred to the degree of control they had over their bodies they used the possessive ‘my’ and ‘I’ in relation to their body. For example Helena stated “physically after I had the stroke I felt I couldn’t control my left foot”. Despite Helena expressing lack of bodily control, she conveyed ownership of her body. This contrasts from other times in the interview when she distanced and objectified her body. Furthermore, participants associated their bodily control with their self-assurance and sense of progress. For instance, Matthew’s sense of control translated as confidence when he described the difference between walking unaided and with a supermarket trolley:

See we walked all around the supermarket the other day and I came home and I was as good as gold. And then we just walked down the road here yesterday and I was absolutely buggered. And I said to me daughter ‘so I wonder what that was?’ And she told me, she said ‘you were hanging on to the trolley weren’t you?’ And that just shows you, security. It was just a matter of getting that self-assuredness back; to get the confidence back.
In this scenario Matthew’s sense of bodily control in walking was directly linked with his ‘self-assuredness’ in general. When Matthew was able to walk around the supermarket there was a sense of it just is – “good as gold”, where his body and self were cohesive. Similarly Helena used changes in her ability to control her leg and arm as evidence of her progress;

At the hospital it was said I’d forgotten I had a left side. Maybe I had for a while but I soon woke up about that. And there at the hospital and since I came home, I’ve managed to get control of my foot but not my arm. My arm is [slaps left arm], I can still feel it, I can feel it, but it’s gone unpredictable.

Helena used the analogy of “waking up” to represent regaining control of her leg, whilst the lack of control in her arm, as previously highlighted, she termed “unpredictable”. Control and unpredictability can be considered as polar and conflicting, yet Helena could feel partially in control and partially that her body was unpredictable. This illustrates a changing relationship Helena had with her body, showing the fluidity of her embodied experience.

*Control over life*

Control also referred to participants’ sense of control in their roles, identity and general existence. For example, George, who described himself as “an active, busy person”, used a metaphor to represent how his wife had taken control since his stroke when he said despondently; “The roles have changed; Mary [wife] is now the controlling person in the house and I’m just the passenger”. This suggested George had adopted a degree of passivity in life roles with an increased dependence on his wife. Furthermore, his
statement implied a sense of lost control which his wife instead had. Thus George’s sense of control over his body not only influenced his ability to walk independently, it also influenced his sense of control in relationships. Similarly Helena described how her lack of arm control influenced how she felt about herself generally;

*What does it make you think when your arm is unpredictable?* That, it makes you wonder if it’s coming, if it will come back. It makes you initially feel as if you’re losing control of yourself completely [chuckles].

*Can you say a bit more about that?* Yes, that is a big shake up. To feel that um, a part of you has well maybe died. That is very challenging.

Despite previously acknowledging an improvement in her ability to control her left leg, she at times still felt she was “losing control completely”. Control of her arm, or lack of it, thus was associated with Helena’s sense of control as a whole. This overwhelming lack of control, for Helena, was to the extent that she felt part of her had died. Despite this strong statement, she later, perhaps profoundly, suggested that we never truly have control of our bodies anyway;

But I think as you get older you’ve got to learn that we just have to take whatever comes, because what comes is going to come, and you haven’t got any control of it anyway as far as your body’s concerned.

Although Helena perceived bodily control fluctuated in life, the experience of stroke appeared to amplify this feeling of having, or not having, control. In this way Helena’s stroke prompted existential contemplation where she questioned the control anyone has over their lives, with a loss of control in life being almost inevitable for everyone. This implies integration between Helena’s experience of her body and her wider beliefs about life, ageing and being human.
In summary, participant’s had a changed sense of control after their stroke including control related to bodily control, control in daily tasks, and in relationships. Participant’s feeling of bodily control could also influence their perception of control in other aspects of their lives. This included prompting some participants to raise existential questions of human agency. In all these types of control, a sense of unity was prevalent, without any division of body and self as evident in expressions of a ‘divergent body-self’ in the same interview.

4.4.2 Freedom

Freedom was referred to in the context of bodily movement and of life choices. Where freedom had been experienced participants spoke of themselves as a whole rather than as having a separate body. Similarly, where freedom had not been experienced but instead was being sought, participants referred to this state in the context of ‘me’. Although freedom, either before or after stroke, was not referred to frequently by participants, when it was mentioned, it was emotive. For instance, George described the freedom of walking without a frame after his stroke.

Walking with a frame is not as free moving as walking without a frame. So I really miss that . . . It’s lovely to be able to walk around here without the frame. It’s quite a free feeling and I can cope.

George alluded to walking with a frame not feeling like true walking as it was not “free”. George also linked this feeling of bodily freedom to his ability to cope and a positive emotion; “lovely”. He expanded on this further and linked the sensation to being a child;
The time that I really found it most was that time I was telling you when the lady [the physiotherapist] said ‘for god’s sake, just walk’. That was freedom. It really was. I can still recollect what it was like, you know, nothing there. I didn’t have to hang on to anything…I suppose it’s something that, all my life I’ve been able to walk everywhere I’ve wanted to…And I think that just being able to do that was . . . I could be subconsciously going back to my boyhood days, I remember that.

George’s first experience of walking after his stroke was vivid. Walking was a positive experience for him as it was something very familiar to him, in the midst of the unfamiliar hospital environment and unfamiliar stroke experience. George’s bodily movement was thus emotive. His feeling of freedom was so resonant in his body that it evoked a sense of being a child. Michael also made reference to walking as a child, but this time it was in contrast to his own lack of freedom in walking;

One of the other surprising things was, in the ward was, er one of the room mates had a great grandchild, 18 months old; walking. You know, at that stage getting up, walking and falling over, whatever. And here we’re basically the same stage... No, it’s good to be able to do that again. But there is still a long way to go. Because when you realize how well you could walk before, to now; that’s a hell of a difference still to go. The things of just getting up and say moving round the kitchen…It’s a lot harder now because you’re on a chair, a wheelchair or something like that, and those movements are hard.

Michael appeared to be in a state of flux between feeling he had some degree of freedom in his walking, to lacking freedom when trying to move around his own home. Like George, Michael described it as “good” to be able to walk and again it prompted him to consider how easy it was to walk before his stroke. This description of child-like walking is in stark contrast to participants like Peter and Matthew, who, as previously mentioned, spoke of concentrating incredibly hard on every aspect of walking. Helena, like Peter and Matthew, did not describe experiences of this freedom but appeared to be in
quest of it. For instance Helena spoke of waiting for her body to become “freer” to enable her to do exercises suggested by her physiotherapist.

Now sometimes I can do them [referring to exercises] twice and sometimes I can’t even manage them twice without putting the foot down or without having more fingers on the bench. So I thought, what does it matter if I don’t do it [referring to the exercise program] this week, I can do it next week or when I’m, maybe next week I’ll feel a little bit freer.

Helena appeared hopeful for more freedom of bodily movement despite having expressed a feeling of being “stuck” like a “vegetable”. In contrast to her otherwise persistent reference to her body as an object with “it” and “this”, when speaking of freedom Helena used the possessive “I”. Similarly Grace took ownership of her body when referring to the freedom of moving her body; “suddenly you’re devoid of being able to use your hand, get out and walk, do you own thing; your freedom’s all gone”. Grace related her sense of bodily freedom to her independence and perceived freedom of choice. This illustrates how Grace’s experience of lost bodily freedom reflected in her entire experience of the world.

In summary, freedom, both in terms of movement and independence, was lost, sought, and sometimes found by participants. For those who had felt this freedom of movement after stroke, there was a link to their pre-stroke existence when they could move freely without thought. Freedom of movement was also associated with participant’s perceived freedom of choice. In this way the notion of freedom made participant’s bodily experience more cohesive and seamless with their overall experience of the world.
4.4.3 Self-identity

The participants’ sense of self-identity at the time of interviewing appeared constant despite their stroke. For some participants, who felt they could no longer be true to their identity, this created a mismatch and confusion. For others, their unwavering sense of self-identity brought them strength and enabled them to speak more coherently of their body and self.

Altered body impacting on identity

Participants described how their altered body impacted on their perceived identity. For example, Helena described herself as being an active person prior to her stroke who “never sat down”. However, the physical restrictions from her stroke including weakness, incoordination and fatigue, caused Helena to spend much more time sitting alone at home as she describes here;

I was an active person.

How would you describe yourself now? A vegetable. A very annoyed vegetable. I don’t like it at all.

Can you explain why a vegetable? Well, um I’m a vegetable because I just can’t seem to, somebody’s got to accompany me whether it’s in the car, if I go for a walk, and anyway I can’t walk very far. That makes me feel more like something that’s planted than a person. I’m stuck at the moment.

This expression of being a “vegetable” related to her dependence on others after her stroke as well as her reduced activity capacity. Thus for Helena her identity directly related to her bodily ability such as being able to go out for a walk. Her lack of ability had
reduced her self-identity to a negative image of a vegetable. Helena attempted to explain this feeling further by describing it as “somebody else” in her body after her stroke;

It feels as if you’ve gone and somebody else is in your place. Not that all that I was perfect, I know I wasn’t. I was a woman who had been hurt by life and couldn’t let go of stuff. But I think I’ve, that’s knocked that out of me. It sort of said very sharply, this is how you got here.

Here Helena appeared to simultaneously be referring to the strangeness of her body, in which “somebody else” had taken over, as well as the foreignness of this body to her identity. For instance Helena spoke of a feeling of being “stuck” which made her feel “lost”; “there’s two parts to that [feeling lost and alone]. There’s the stroke part and then there’s the getting used to the loss of what you perceived to have been yourself”. She suggested that there are specific bodily effects of the stroke which made her feel lost but that she had also lost a part of her identity as she was unable to engage in the activities she valued. Likewise Helena expressed a negative, critical relationship with her body;

*Do you feel different about yourself when you’re alone, versus when you’re with your friends, versus when you’re in public?* When I’m just on my own such a lot I begin to think, you’re just a big blob of nothingness and that’s not pleasant (starts to cry).

Helena’s reference to being a “blob of nothingness” appeared to be in reference to both her sense of body and sense of self. Although this was a distressing experience for Helena there is a sense of cohesion between how she viewed her body and herself as a person.
Enduring identity in spite of changed body

At other times participants described an enduring identity despite their bodily inability to match the characteristics they associated with their self-identity. The presence of an enduring identity appeared to minimize the degree of bodily strangeness participants experienced. For example, Peter, who described himself as “an active person” stated:

Those are the things that disappoint me. Cos I’m so used to doing, being on my own and doing my housework, doing everything, and being tidy I suppose. And it’s really a matter of thinking well, no I’ll do that tomorrow, I won’t deal with that today, I won’t do this and this and this, I’ll leave that couple of things to tomorrow, or the next day. There’s no hurry. That’s what I probably was disappointed mostly with; I thought I was going to be a superman again around here.

Here there is a mismatch between Peter’s sense of who he felt he was; “a superman” and then what his body would allow him to do in terms of housework. This created a strong sense of disappointment for Peter. However, despite this disappointment and mismatch of identity and ability, his identity was also helpful in making sense of his post-stroke experience;

I mean my friends that I have a beer with and all that you know, they can see that I’m alright mentally and everything like that, it hasn’t affected that. So they don’t sort of you know, they were concerned for the start but they’re not now. I just join in and carry on, just do everything myself as much as I can you know...just be one of the group really, yeh.

So in spite of Peter being physically less able after his stroke, his sense of mind and identity remained intact, enabling him just to “carry on”. Thus Peter’s constant identity almost overrode the profound change in his bodily ability. Michael’s experience echoes this notion of bodily change, yet sense of being the same;
Yeh I don’t feel there’s any changed image. Maybe in the fact that for a while I’d be walking along there slower, with a walking stick and everything like that. But that’s something for me to work on and get ahead of that, round the corner.

Despite Michael’s change in walking ability his body image remained a constant for him. He spoke positively about his future ability to walk and minimized the problems he had with his walking at the time. The way that Michael moved between present, past, then future tense indicates the fluidity of his self-identity within his embodied experience. Similarly, George oscillated in the way he described his sense of identity in both present and past tense;

I play golf on Mondays, bowls on Tuesday, and I play golf on Thursday, and I play bowls on Friday and I play bowls on Saturday. And I mow the lawns. I’ve got a garden out there that I used to do. I walked every day. Yep, I was active.

Although George used past tense, “I was active”, he used the present tense to describe his leisure activities. Thus despite not playing golf and bowls at the time of interviewing, George had an enduring identity of being a golfer and bowler. This conflict in bodily ability and simultaneously held identities suggests self-identity could diminish the divergence participants experienced in their body and self. Similarly Helena spoke of conflict in how the left side of her body felt different yet she felt the same about her body;

Do you feel differently about your left side of your body as a result? No I don’t think so. It is different, but I’m not feeling differently about it. It’s still me, but it’s, this part of me [slaps left thigh] is just the same as usual, lots of my leg is just the same as usual [slaps left leg].

Helena inferred her body as being different and yet stating her body is “still me”.

This example illustrates the dilemma that participants had in making sense of a profoundly
different body, and yet a feeling of continuity pre- and post-stroke. This dilemma is further demonstrated by contradictions participants made in their sense of changed versus unchanged self. For instance, George made the following response after being asked if he viewed himself differently after his stroke:

View myself differently? I’m no less a person than I was before; mentally or physically. Physically of course I am but that’s ok. If somebody was to hold that against me, well I could hold it against them just as easy. But no, no I feel as though anybody, any of my friends or places that I knew about; I’d be no bigger or lesser in their eyes. And if they did, well stuff them.

George’s immediate contradiction of his physical status as “no less” but yet “of course” being changed following his stroke is striking. This perhaps suggests that George was at a transition point in what he viewed as being different for him, yet identifying as the same person. Alternatively, his contradiction may reflect the state of flux between a divergent and cohesive body-self.

Enhanced identity

One participant, Helena, described how despite an often frustrating bodily experience, her stroke had enhanced her identity. Helena expressed how the stroke had been both “terrible” but also a positive experience. In one of the phone calls leading up to the interview Helena talked of how her stroke had helped her to “let go” of previous anxieties;

I just feel so different from myself. I used to be the sort of person who ran everywhere. I was full of life and running everywhere; pretty healthy. And I know I wasn’t the sort of person who could get over things easily, and I used to pine for people. I know I didn’t get over rejection, I was terrible with
rejection……I really do think that since I had my stroke, that that part of my life has gone. I don’t think about it at all really.

*And how do you feel about that?* Pleased. Because it was like being haunted.

*It sounds as though the stroke has changed you in several ways. Do you think it’s changed you in a good way or a bad way?* I would say in many ways, a good way because it isn’t very good to be so sensitive. I think having the stroke, in some ways, has hardened me up. (Phone call week 3)

Although Helena recognized that she was different both in a bodily and identity sense, and alluded to being less active after her stroke, she described positive changes in her approach to life. Helena’s ability to cope better emotionally after her stroke perhaps indicates some form of resilience and personal growth.

In summary, there was often conflict in participant’s statements about what had and had not changed since their stroke, which illustrated the renegotiated notion of ‘what is me?’ The contradictions expressed about feeling ‘the same’ versus feeling ‘different’ suggested that although the stroke resulted in a different physical body, people were able to maintain, to a large degree, a coherent sense of self, although this varied between participants. Control, freedom and identity all contributed to a sense of cohesion and unity between body and self. These attributes were referred to positively and were something which participants strove for, or spoke fondly of if they had already experienced them after their stroke. However, these concepts also applied to the experiences of a ‘divergent body-self’ with participants being in a state of flux between a divergent and cohesive embodied experience.
4.5 Anchors

Participants described a range of factors that appeared to ground and thus reassuringly anchor them from what was often a confusing and unfamiliar embodied experience. Participants reported an “unreal” experience after their stroke which related to their body. However, a number of factors anchored the participants in a more comprehensible and coherent bodily experience. These factors can be summarized as knowledge, attitude and environment. Often these anchors emphasized a more cohesive bodily experience influencing participants to feel, or be moving towards a feeling, that ‘it’s all me’. However, there were also times when anchors influenced participants to feel more comfortable and familiar with how they experienced their body despite it being divergent to their sense of self. The anchors of knowledge, attitude and environment can therefore be viewed as assisting participants in their journey to adapting to their embodied stroke experience, irrespective of the extent that this was an experience of a cohesive or divergent body.

4.5.1 Knowledge

Knowledge included general knowledge of stroke physiology and recovery as well as knowledge participants gained of their own post-stroke body. ‘Knowledge’ can be considered as being factual, but also, in the context of this study, is used to express greater insight – in other words, meaning gained through personal reflection and interpretation of experience. New knowledge enabled participants to make sense of their post-stroke body and to regain a sense of control over it. This helped participants to make sense of why they
were experiencing their body differently after the stroke, and this understanding provided reassurance. Furthermore, knowledge of their body allowed them to modify everyday activities to allow for their changed bodily limits. Knowledge about stroke and its effects was acquired by participants through learning about their own body and consideration of the underlying physiology.

Learning

Many participants described learning about their post-stroke body within the world around them. For example Michael stated “But at home um, no it’s more of a development process of what’s been learnt at the rehabilitation, and working on that to improve it”. This indicates that Michael continued to be learning at the time of interviewing, one month after leaving hospital. He went on to explain how he learnt to concentrate to help him to walk:

It’s [how to walk] just something you learn as you’re being developed. You concentrate on them [rehabilitation activities] to do it because then you have to do it again. So the quicker you learn to do it [walk], the quicker it comes right.

Michael perceived that learning through concentration would enable him to resume bodily control again to walk. For others, learning was in willing their body to persist beyond their perceived limitations. Grace spoke of how she learnt to persevere in rehabilitation in order to regain bodily control despite the effort it took:

..they had a beautiful gym there and you know these girls would take me on these different things and it was wonderful. But I was sort of saying to myself I hope it’s soon over, I can’t do this for much longer. This is much too much for me, you know. And that sort of attitude, which is so wrong, but I couldn’t, I couldn’t get all fired up. Yeh, it was a learning process.
Despite Grace viewing the gym sessions as somewhat torturous she summarized it as a “learning process” which was “wonderful” as she learned a new way of being in her body and what her body was capable of. Other more specific insights she described about her post-stroke body included how she needed “space between [her] legs” to walk. Together, this knowledge made her persevere with walking practice despite her “dreading” the thought;

And you know I would dread at the thought of sitting in a chair like this and then having to get up with the help of one of those [indicates frame] and start walking. And you know the tendency is to say, ‘oh give me a chair and let me sit down’. But I think no I’ll persevere because I want to get to the walking. And my walking has improved a lot, but I can feel myself I’ve got to discipline myself; left, right, left, right.

Here discipline was linked with progress for Grace, and bodily control allowed a more positive experience of walking. This was in spite of Grace acknowledging the effort of walking with her self-described “tendency to give up”. Thus she learnt that the effort was worthwhile in helping her to return to walking. In this way Grace’s learning about her body anchored her into a more acceptable experience of her body in what was otherwise a challenging and confusing time after her stroke.

Participants’ experiences of learning about their bodies was often inextricably linked with insights into their post-stroke self-identity. Like Grace, Helena spoke of learning about her new sense of self: “Well, I can’t move around, I can’t do the things I used to do. I’ve got to learn to be whoever I am, now and for the rest of my life. And that takes time”. Helena connected bodily movement with her sense of self, indicating that she was not just learning to live with a changed body after stroke, but also a changed sense of
self reflecting an adjusting identity. For Helena, there was cohesion in the way that her body and her sense of self had changed after stroke, albeit in a way that was challenging for her. She alluded to learning about her new self as helpful in adjusting to her future. Like Grace, this suggests that knowing who she identified as anchored Helena in an embodied experience that she found more acceptable, albeit challenging.

**Understanding physiological changes**

Participants made sense of their bodily experiences by trying to understand what may be happening physiologically since their stroke. For instance, Helena considered why she had sensory changes in her arm;

But that part [taps left arm] I feel a slap more keenly there [indicates left wrist] than I do there [indicates left upper arm]. So the nerves must be affected differently at different little…they must come in little groups. And some go that a way and some go that a way.

Like several participants, Helena had formulated her own understanding of what was happening at a physiological level in order to make sense of her strange bodily experience. This clarified for her why she had altered sensation. Similarly George, explained a theory he had about neural plasticity based on wiring; “my thinking is that the brain is wired one way and if I can get something that can connect those little wires together and change it”. George’s perspective of neural plasticity, like others, was empowering for him as he perceived that this was something that he could change. Similarly Grace also talked of her perception of unconnected nerve endings in her brain. She expressed a determination, quest even, to get these nerve endings to meet;
And I didn’t really know, I think I had this picture of a brain or of a something and it sort of showed all these lights or not wires but I suppose they were nerve endings that weren’t joined to anything. And it sort of threw me because I thought I’ve gotta get those to meet each other.

Consideration of the neurological basis for bodily strangeness appeared helpful to Grace. This understanding was therefore reassuring and anchored participants in a more acceptable embodied experience despite their body feeling strange and unfamiliar.

In summary, knowledge and understanding through rehabilitation, and personal insights after stroke, was associated with participants reporting a more accepted embodied experience, usually cohesively. Participants’ knowledge about their post-stroke body explained and clarified their new experience which helped them to accept the changes in their body.

4.5.2 Attitude

The participants’ attitudes also appeared to anchor them to a more personally acceptable embodied experience. Attitudes included their personal outlook and sense of higher purpose. Participants’ attitudes often lead them to speak of a more cohesive body-self, but at other times enabled them to speak more positively of the divergent body-self. For some participants, their attitude reflected a sense of resilience and personal growth from the stroke. For other participants however, fear could ‘de-anchor’ them to create anxiety and uncertainty about their bodily experiences.
**Personal outlook**

All participants spoke of their individual approach to their stroke recovery. Their approach was closely intertwined with how they interpreted their bodily experience. For example, George spoke of his personality trait of being “determined” and how this helped him to deal with the challenges of bodily activities:

I’m a reasonably determined person, and if I can’t do something, I thought oh I was a practical guy; I was a builder, and a cabinet maker and that sort of thing. And you notice you do things sometimes that you think ‘that’s gonna be tough to do’. But anyway, you get stuck in and do it. So I’m reasonably determined. Not stupid, determined. So yeh [physiotherapist] was always getting me to do things which were very difficult to do. And I can absolutely see where she’s coming from. Cos when you went back next time you might just say ‘we’ll run over those’ you know. And you know it’s quite surprising how easy it was the second time.

George’s determined approach to life assisted him with the challenges of attending physiotherapy where he was being pushed physically. In this way George’s personal outlook enabled him to view the difficulties of regaining bodily control more positively.

Personal outlook also included the participant’s sense of hope which featured strongly throughout interviews. References to hope were often coupled with expressions of the challenges of their post-stroke body. For instance, when I asked Don what it felt like to lift his arm he replied “It’s er heavy. It just stops…try to pick it up every day. I hope, I hope, I hope it gets higher”. This sense of hope appeared to help Don tolerate the frustration of being unable to lift his heavy arm. He almost used hope as an approach to his recovery as he perceived that nothing had been useful in his recovery: “What things have you found useful in terms of making progress? Nothing useful…go training [therapy]
and you can’t touch it. I hope, I hope, I hope, I really do hope”. Thus hope made Don better able to cope with his lack of bodily control despite his effort in therapy.

For others hope was more of an outcome of having made physical progress. For example George reflected “I couldn’t even stand up. And now I’m walking so, so I’ve got hopes”. Here George’s bodily experience had enhanced his personal outlook, allowing him to hope for further progress. Thus hope could impact on bodily experience and bodily experience could impact on hope; further illustrating the fluctuating nature of the embodied experience. Participants described consciously applying hopefulness in order to achieve better outcomes. For instance Michael stated “your progress would be hindered if you weren’t positive. There’s only one direction I want to go”. He made this connection with being positive and hopeful to making progress in his ability to walk. This indicates how attitude could be purposefully utilized to improve the embodied experience of stroke.

*Higher purpose*

Participants described how a sense of purpose beyond themselves such as religion or metaphysical meaning could empower them in the face of adversity after their stroke. Higher purpose was especially mentioned as participants reflected on lost bodily control and strangeness. For example Grace often responded to questions about her body with a connection to her faith;

I can put my faith in God and that any spirit of fear that I can feel is not real because God’s spirit gives me power, love and a sound mind. And they’re positive things and I cling to them, yes. It’s been a real blessing to me. ….. I know God’s brought me this far and I’m very grateful.
Grace spoke not only of how her faith helped her to cope but also of how her stroke appeared to affirm her faith in God. Furthermore Grace’s belief in God gave her strength to manage the fear she had after her stroke. Grace alluded to having experienced personal growth as a result of her stroke, with a strengthening of her relationship with God;

I think it’s made me realize I’ve got to get more depth, yes. And I think it’s made me more dependent on God I think. You know when you’ve got full health and everything you don’t need anyone do you.

Grace suggested that she was still in the process of developing this relationship she had with God by saying “I’ve got to get more depth”. This indicated a dynamic process, one based on spiritual developments, not necessarily physical ones. Similarly Helena spoke of how her sense of higher purpose anchored her more comfortably in her ageing and post-stroke body.

You just, if you haven’t got a god I feel sorry for you because I think you’ve got to have, there’s got be something up there that’s a higher power than myself. But I think as you get older you’ve got to learn that we just have to take whatever comes, because what comes is going to come and you haven’t got any control of it anyway as far as your body’s concerned.

Helena made a connection between her sense of higher purpose and bodily control, suggesting that her belief enabled her to accept any changes in her body. It appeared that Helena’s physical body was perhaps less important to her than her higher purpose, especially as her body aged. There is also a note of inevitability in both Grace’s and Helena’s statements which appeared comforting for them. Helena’s and Grace’s spiritual focus indicate that personal belief systems were pivotal in coping with the effects of their stroke but also in creating a more accepted embodied experience.
**Effect of fear**

Separate from the aforementioned positive attitudes, participants also described the effect of fear of their body failing them either in the past, present or future. Fear seemed to destabilize or ‘de-anchor’ participants by creating uncertainty and anxiety about their body. For example Grace spoke repeatedly of feeling scared in relation to a fall she had had when she was getting out of bed;

And I did have a scary experience, because I did. The other girl was an excellent nurse and I wouldn’t want to put her down in any way. But I don’t think she realized how very sort of unstable I was, mentally and physically. And I fell down here [indicates side of bed], and it’s made me very scared. I’m terrified that I’ll get that nurse again.

Fear was directly linked with Grace feeling unstable “mentally and physically”, thus vulnerable. Her bodily experience was one of anxiety and fear whenever she got out of bed or saw that particular nurse again. Matthew and George also described how their fear of falling impacted on their use and experience of their body. Matthew had fallen when walking to the mailbox and struggled to get up. He was subsequently very cautious about walking outside. Similarly George had fallen when in hospital and described how his behaviour had changed when in public places, primarily because of his fear of falling;

We go out occasionally for coffee and I’ll always take the trundler, mainly because I don’t want to fall flat on my face in the coffee bar. And everybody be running around, fussing over me.

In all instances fear influenced participants’ relationships with their body which were viewed as less predictable and controlled since their stroke. Thus fear ‘de-anchored’
participants to an unstable experience of a body which failed, or threatened to fail them. This influenced what they were willing to attempt with their post-stroke body.

In summary, participant’s positive attitude helped them to feel more at ease with their body and self, be it a cohesively or divergently experienced body. Positive attitude included personal outlook, and higher purpose, both of which appeared to stabilize participants in what was often a blurred and strange experience. Furthermore, participants’ attitudes elevated their sense of personhood despite a changed body, eliciting a degree of resilience. Conversely, fear appeared to ‘de-anchor’ participants by heightening their experience of a lack of bodily control and unpredictability. Thus participants’ attitudes were influential in their embodied experience, with positive attitudes being helpful and fear being unhelpful in reconnecting with their bodies after stroke.

4.5.3 Environment

The environment also anchored participants to a particular bodily experience following their stroke be it the social, physical or rehabilitation environment. These environments influenced the embodied experience for participants either drawing them more towards the ‘divergent’ or the ‘cohesive body-self’.

Social

Family or friends had a pervasive effect on the participants’ experiences of their bodies after stroke. The connection participants made with family was often directly
linked with their perception of their body and themselves. For instance, when I asked Peter about his view of himself he spoke of his positive attitude and family:

*So it sounds like you used to be a very active person and identified as being quite sporty. How do you view yourself now?...Um, I've got, no I'm alright, I'm positive every day about everything, you know. But I'm lucky I've got my children here in Christchurch and they keep an eye on me and everything you know so. No I'm fine really.*

Family were a contributing factor in Peter’s feeling of being “fine”. Throughout the interview Peter followed a statement of his struggle post-stroke with a statement of what helped him, often in reference to friends and family. Furthermore, Peter deliberately responded to people in a way that aligned with his pre-stroke identity, as someone who was capable and “normal”. For example:

*What do you say to people when you try to explain those ongoing things that come with the stroke? I don’t really say anything about it. I mean people have asked, some people have asked me you know, what’s happened to you, cos I like that being on [indicates ankle brace on left foot], that’s a great help. I just say I’ve sprained my ankle, and that’s all I say. But I um, I don’t really talk about it a lot...I just join in and carry on, just do everything myself as much as I can you know.*

Peter appeared to interact in ways that minimised his physical changes, and emphasized himself as the same person he was prior to his stroke. Peter’s dismissing of his foot drop as a sprained ankle suggests an unwillingness to share his stroke story to any great extent, allowing him to avoid this becoming a major component of the self-narrative he projects to others. Thus, the way Peter chose to engage with others in his social environment reinforced his cohesive body and self.
Other participants gave examples of how the social environment anchored them to the divergence between their body and self. For example Helena described how she felt differently about her body in different company: “When my friends are there I feel so happy to see them. And I feel ok about me. When I’m out in public I feel a bit mad with myself because I’m so, so handicapped.” The social environment had a considerable impact on Helena’s embodied experience. Helena recognized the influence of others on her internal experience and mused about how being in the company of others might help her to feel less “stuck”;

Well, at home things are different. I was in control of my car, my house, my housework, shopping. I cleaned my windows, I liked going visiting people. Now I’m grounded. Somebody else takes me. I’m stuck at the moment. How does one get rid of that stuck feeling?

*What do you think?* Well, I think you’ve got more chance of doing it if you’ve got, I think maybe perhaps when there’s more company around it might be easier. But certainly being, feeling so lost doesn’t help [crying]

Even though Helena was aware of the impact of the social environment on her body, she remained heavily influenced by this environment. Thus in this situation the social environment was both the amplifier and the minimizer of a divergent body and self.

*Physical*

The physical environment also anchored participants to particular embodied experiences. Physical surroundings influenced how participants experienced their body and how effectively they executed physical activities like walking. For example, Michael
drew comparisons about what it felt like to walk in the hospital setting versus his own home;

Right, you get around at the hospital in a certain way, you know walking and things like that, and the wheelchair. You get home and it was a struggle to get up the steps, a struggle to walk in the passage even with the walking stick, everything like that.

Michael’s home, at least initially, emphasized a divergence in his self and body in which it was effortful to move. Later Michael said he viewed this as a “learning experience” and alluded to his eventual mastering of how to move more freely within his home. Many participants made a distinction between their experiences of their body when inside their homes compared to moving outside, such as George who relayed;

I have my good days and bad days but on a good day I could put that [walking frame] aside and not even use it all day. But I wouldn’t go outside without it. No, if I’m inside there’s different things I can grab hold of, if I need to, which I haven’t.

George’s confidence in his body’s reliability was dictated by the environment around him. Thus George experienced his body as free when walking indoors but restricted and somewhat frightening when walking outdoors. Similarly Peter spoke of the effort of doing domestic chores as well as simply walking. Having a small home had minimized the degree he had needed to exert this effort;

If I had of had my other house I had, the big house, a three-story house, I don’t know how I would’ve got on. The way it’s turned out really, it’s probably worked out alright for me really, with not much to do.

Peter’s reflection on the physical layout of his current and previous homes indicates that the physical environment diminished how often he experienced a divergence between
his physical body and sense of self as capable and independent. This theme of ‘environment’ relates to ‘knowledge’ as participants learnt what to expect of their bodies in particular physical environments.

Rehabilitation

Like other environments, rehabilitation emphasized either the divergence or cohesion between the participants’ experience of their body and sense of self. The rehabilitation environment included the staff and the daily routine of inpatient facilities. For example Michael drew the comparison of how he felt walking with one of the hospital physiotherapists compared to at home with his wife:

When you’ve got people walking with you, some people are very much easier to walk with. And er, one of the physios was sort of always wanting you to walk with your hand up and do things that were unnatural. Whereas others walking along and you feel comfortable and it’s a lot better. So my wife’s a registered nurse, which is, well she’s brilliant [tearful]. She’ll walk behind and in what I call ‘truck and trailer’ [laughs]. And just it’s a matter of balance more than anything, er the fact of security, just a hand barely on the hips, you hardly feel it, but it just gives you that confidence.

The unfamiliar experience of walking with the physiotherapist appeared to exaggerate Michael’s feeling of bodily strangeness. Conversely, he felt “comfortable” and “better” when walking with his wife who, although still providing some physical support, allowed walking to feel “easier” and more natural for him. Thus the normalcy of walking with his wife appeared to anchor Michael in a more cohesive, familiar embodied experience.
For other participants the rehabilitation staff played the role of anchoring them into a more comfortable experience of their body and self. For example, Grace described a heightened comfort with her post-stroke impairments and abilities when in the company of a particular staff member who enabled her to feel hope for the future.

They sent me to [the hospital] and um, it was quite amazing going there. An experience I never dreamt I’d ever have. Suddenly you’re devoid of being able to use your hand, get out and walk, do you own thing; your freedom’s all gone. And there you are sort of at the mercy of the kindness of others…But I remember there was one sister in particular who was wonderful to me and she, I sort of longed for her to be on duty because um, she would talk to me about a future, and ask me what I wanted to do, and you know, opened a new avenue for me.

Although the notion of feeling “devoid of being able to use your hand” and having “an amazing” experience seem incongruent, the rehabilitation staff enabled Grace to visualize a future for herself. This knowledge of life after stroke enabled Grace to think cohesively as ‘me’ rather than in terms of a body which could not move.

The rehabilitation environment also included the influence of therapy on the participants’ bodily experiences. For instance Peter enjoyed the feeling of physiotherapy sessions; “So I’ve been doing them [exercises] everyday...she [physiotherapist] really worked me hard and I really enjoyed it.” Peter especially enjoyed the experience of doing exercises despite it feeling hard. When asked what his body felt like when in physiotherapy Peter said “Oh good, yeh good” which is in contrast to other times when he described his body as feeling “very strange”. This suggests that the physiotherapy environment influenced how he experienced his body, enabling him to feel pleasure as he moved instead of feeling “terrible” like he’d expressed at other times.
In summary, the environment surrounding participants influenced their bodily experience anchoring them more clearly and comfortably in either a more cohesive, or sometimes a more divergent relationship between their body and self. Environments included the social, physical and rehabilitation environment but these settings influenced participants in differing ways. Thus the environment, like other anchors, was idiosyncratically influential for participants in their embodied experience of stroke.

4.6 Summary of the embodied experience

The embodied experience of stroke one month after leaving hospital was complex, idiosyncratic, and dynamic. The bodily experience after stroke is altered to the extent that it can cause people to question their self-identity, lose hope for their future and impact on their sense of control over their lives. Participants expressed experiencing a body which was divergent from who they were as people; a body that was strange, effortful and unpredictable. Conversely, and at times concurrently, participants spoke of a sense of wholeness in spite of a changed body. Knowledge, attitude and the environment appeared to influence this embodied experience considerably.
Chapter 5: Discussion

5.1 Introduction

In this chapter I discuss how the findings of my study reflect and advance existing understanding of the embodied experience of stroke for people transitioning from hospital. In particular I postulate that the bodily experience of stroke extends far beyond the physical body, and question what this means for the physiotherapy profession whose focus arguably remains centred on physical experiences. I also reflect on my personal journey and experiential learning through doing this research, and consider what this may mean for fellow physiotherapists. Finally, I suggest some of the limitations but also implications that this study has for clinical practice and recommend areas for further research.

5.2 The body and sense of self as intertwined

The substantive finding from my study is that the bodily experience of stroke is intimately related to a person’s sense of self; with my references to self meaning “the experiencing subject” (Leary & Tangle, 2012, p.2). At times it was the differences between a stroke survivors’ body (physical) and sense of self (subjective) that were intensified, whilst at other times it was the unity of body and self that was illuminated. This interplay between body and sense of self after stroke contrasts with the commonly assumed view that holds the experience of body and the experience of self as synonymous or inseparable. Indeed, the experience of stroke can challenge stroke survivors’ own perception of the relationship between their body and their self. However, there is no
standard trajectory for all stroke survivors regarding this phenomenon. Instead the relationship of body and self is idiosyncratic, evolving temporally and contextually, and can be particularly challenged when transitioning from the hospital to home.

5.3 Divergence in body and sense of self

Experiencing a body that was strange reverberated through all interviews, as it has done through previous studies. Words synonymous with bodily strangeness are commonly found in descriptions of the body being ‘divergent’ from a person’s sense of self after stroke. Strangeness has been described by others as “alien” (Arntzen et al., 2014, p.10; Charmaz, 1995, p.662), “fragmented” (Arntzen et al., 2014, p.10), “foreign” (Faircloth et al., 2004a, p.75), “separate” (Ellis-Hill et al., 2000, p.728), “odd” (Arntzen & Elstad, 2013, p.69), “unhomeliness” (Leder, 1990, p.24), or “a body that is not me” (Kitzmüller et al., 2013, p.24). Thus bodily strangeness predominates the profoundly new bodily experience many stroke survivors have, segregating life-before versus life-after stroke (Arntzen et al., 2014; Ellis-Hill et al., 2000; Faircloth et al., 2004b). This resonated in my study with descriptions of life after stroke being “a whole new ballgame”, “a new world” and “an unreal experience”. At face value, this is perhaps not an unexpected finding. However, the way in which bodily strangeness so powerfully impacted on participants’ perception of themselves, was particularly striking for me. The resulting divergence between participants’ perception of their body and sense of self meant that at times people viewed their body from an outside perspective, as if their body was separate from what they considered as ‘me’.
Divergence of the body from self after stroke has been described by other authors like a new relationship between a person’s body and his or her mind, with conversations happening between the two (Ellis-Hill et al., 2000; Merleau-Ponty et al., 2004; Pallesen, 2014). Central to this changed relationship is the way that stroke survivors in this study, like others, often viewed their body as ambiguous with a sense of detachment and often objectification (Charmaz, 1995; Kitzmüller et al., 2013). This was frequently evident amongst my participants, with people commonly referring to their own body as an article. Objectification has been suggested to serve as a defence mechanism in that perceiving the body as machinery could reduce the impact of the body’s failings (Thomas & Wardle, 2014). By deliberately separating oneself from a failing body, Thomas and Wardle (2014) propose one’s being does not need to be embodied by its physical shortcomings. I believe that the participants in my study were often unaware of the divergence which had occurred for them between their body and self, and this was instead a subconscious process. In fact I asked one participant why he referred to his leg as “it”, to which he replied “I didn’t realize I was”. Thus although divergence in body and self is common in stroke survivors, it is not an embodied experience that people necessarily have insight into.

The experience of a separate body and self is strikingly similar to Descartes largely rejected theory of Cartesian dualism (Goldberg, 2011). Perhaps ironically, a dualistic view of one’s body and mind, be it consciously or not, and be it helpful or not, is seemingly unanimously experienced by people after stroke. However, unlike Descartes’ notion, stroke survivors embodied experience was dynamic being in a state of flux between dualism (divergent) and a more whole (cohesive) experience of body and mind.
True to bodily divergence from self, participants described a new mind and body conversation, as suggested in previous research whereby “the mind is telling the body - which is not listening - what to do” (Faircloth et al., 2004a, p.75). Instead, stroke survivors like my participants, have described how their mind had to instead listen to their body, with a resulting heightened awareness of their body. This awareness was often described by participants as forced and negative, and has been termed in previous literature as “body dys-appearance” (Bullington, 2009; Leder, 1990, p.26). “Dys-appearance” with ‘dys’ meaning abnormal, difficult or bad, refers to times when the body is forcibly present and appears as something bad (Leder, 1990). This is in contrast to everyday situations where the body is not often thought about; it “dis-appears” (Zeiler, 2010, p.335). Strikingly, the experience of bodily dys-appearance was reported by my participants irrespective of the level of their impairments (World Health Organization, 2001), with seemingly minor impairments having significant effects on participants awareness of their body. Importantly, this suggests that the embodied experience of stroke is not dependent on stroke severity.

The challenge which occurred for my participants, and which is mirrored in other studies (Ellis-Hill et al., 2000; Kitzmüller et al., 2013; Kvigne & Kirkevold, 2003), is that their body, which participants were trying to listen intently to, had become unpredictable. This was due to a variety of reasons such as weakness, incoordination and fatigue, all of which translated into a distrust of their own body. Body unpredictability overlapped with a sense of effort that participants experienced when attempting everyday activities like dressing and walking. Other studies have acknowledged body unpredictability with the
synonyms “demanding” (Kvigne & Kirkevold, 2003, p.1300), “perplexing” (Ellis-Hill et al., 2000, p.729), and “fragile” (Kitzmüller et al., 2013, p.22). As a consequence of unpredictability the post-stroke body dictated people’s ability to function, which in turn, affected their ability to do not just everyday activities, but also the activities which they felt made them ‘them’. Thus, at times, the physical body had not only become central to awareness but also consumed self-identity. In this way the body ‘becomes’ stroke, like pain and chronic illness have also been described to do (Bullington, 2009; Charmaz, 1995). When the “background becomes the foreground” (Bullington, 2009, p.106) like this, stroke encroaches into a person’s perception of him or herself, which is considered the social construct of self-identity. This amounts to an experience of living in a body that is “not me” (Kitzmüller et al., 2013, p.24). Consequently, having a changed physical body after stroke had a profound effect on peoples’ entire perception of themselves and of them in the world.

5.4 Cohesive body and self

Concurrent to the experience of a body that was divergent and “not me”, participants also described an almost paradoxical sense of cohesion between their perception of their body and their sense of self. The cohesive body-self represents both a unity and an overflowing of characteristics between body and self. This overflow could occur in either direction between body and mind so that, for instance, freedom of movement could infer existential freedom, or alternatively a sense of being an ‘active’ person could override an opposing bodily experience. Furthermore, some people alluded to a sense of personal growth and enhanced self-identity after their stroke. As such, the
embodied experience of stroke was not a static state, but instead could be influenced by temporal, contextual and intrinsic factors.

All participants related their bodily experiences after stroke to their sense of personhood, indicating that self-identity is significant in the embodied experience of stroke. Importantly though, participants’ self-identity was evolving, being viewed relative to their own interpretation, as has been identified by other studies (Ellis-Hill & Horn, 2000; Kitzmüller et al., 2013; Pallesen, 2014). At times, it appeared having a stroke prompted people to question “who am I?”, whereas at other times the stroke appeared to affirm participants’ sense of self. Self-identity in the presence of health conditions has been identified as a complex concept and there are a multitude of proposed theories (Levack et al., 2014; Sivertsen & Normann, 2014). Central to these theories is the sense of changed assumptions in self, and the dynamic nature of self-concept. In particular health conditions have frequently been reported to make people question previous assumptions of who they believed themselves to be (Bullington, 2009; Levack et al., 2014); with no apparent relationship between physical ability and self-concept (Ellis-Hill & Horn, 2000). This was echoed in my findings, with the most severely affected participants appearing to often have the strongest sense of self-identity.

It has been suggested that to maintain a strong identity people need to perceive their core self as constant and continuing, despite other aspects of oneself, like the body, constantly changing (Faull & Hills, 2006). An altered perception of self-identity, with uncertainty about previous assumptions of the world in the presence of an event, such as a
stroke, has been described as “a biographical disruption” (Bury, 1982, p.168). Although participants in my study identified a fundamental change as they entered a “new world” after stroke, what was more predominant was a sense of “restructuring” (Levack, Kayes, & Fadyl, 2010, p.995) of the body-self and world relationship. This reverberates in other studies of stroke survivors, with the proposal instead of a “biographical flow” whereby “stroke can be integrated with various social contingencies in constructing a biography that continues to flow across space and time” (Faircloth et al., 2004b, p.256). Similarly, through the ageing process, a number of clashes between a person’s body and sense of self have been described with resultant reframing of self-identity (Cott et al., 1995; Thomas & Wardle, 2014), also described as “the narrative self” (Gallagher, 2013, p.20). This notion resounds with the stroke survivors in my study as they spoke of a quandary of reframing their self-identity in relation to their bodily experience. As part of this reframing, people, either ageing or in the presence of health conditions, have been said to make identity trade-offs whereby they readjust activities so as not to reveal their inabilities, enabling them to preserve their self-identity (Charmaz, 1995). Part of making trade-offs means prioritizing what is important, which was evident amongst my participants, with consolidation of what they felt to be important. This quandary was only partially resolved at the time of interview; possibly reflecting the transition phase, but maybe also reflecting the ongoing biographical flow process we have through life.

The cohesion between body and self was often, but not always a positive experience. For instance a loss of physical abilities was at times reflected as a loss of self-identity amongst participants. This can be seen not simply as a disruption to self-identity,
but as a profound loss of self, as reflected by Murray and Harrison (2004) in their study of stroke survivors. Consequently bodily strangeness could infer a strangeness also in their own personhood (Murray & Harrison, 2004). The degree and emotional effect of my participants’ embodied experience was idiosyncratic in that it manifested differently for each person, reflecting the complexity of this experience. For instance some participants spoke of grief and loss after their stroke, whereas others alluded to a sense of personal growth. Gadow (1980) argued that there are two directions that a person can take when attempting to restore unity between their self and body: “renewed dichotomy” and “a new unity” (p.176). However, there was not such a dissection in my findings, instead a fluid spectrum between dichotomy and union which participants moved between both within a moment and over time. Furthermore the cohesive or divergent body and self was not polarized, either conceptually or emotionally, instead being orthogonal. This is an important aspect of the embodied experience of stroke as it means both the process and outcome are idiosyncratic as there is no single route or goal; what is acceptable for one stroke survivors may not be acceptable for another.

Consequently the relationship between a ‘divergent’ and ‘cohesive’ body-self was highly dynamic and impressionable. This experience mirrors that of recovery and adjustment generally after stroke, which has largely been described as “non-linear, ebbing and flowing over time, presenting successes and setbacks” (Sarre et al., 2013, p.721). As such, the embodied experience of stroke, like recovery, cannot be viewed as a simple process but instead seen as a “life-long project” (Kitzmüller et al., 2013, p.27). However, my study emphasizes the particular turbulence in people’s relationships between their body
and self on leaving hospital after stroke. As Arntzen et al. (2014) has also suggested, this may be due to homecoming forcing stroke survivors to make sense of their changed perceptions of body, participation in everyday life and sense of self, unlike in hospital where institutional settings ‘normalize’ an otherwise profoundly strange embodied experience. Institutional settings have been said to postpone the uncertainty and grief of the embodied stroke experience as people are surrounded by others with stroke, but also because health care professionals do not embark on discussions about the tensions between stroke survivors’ perceptions of their bodies and senses of self (Arntzen et al., 2014). Instead, stroke survivors are left to make sense of their bodies and selves when they have left the security of hospital (Arntzen et al., 2014).

The other component of body-self cohesion after stroke was the perception of control and freedom; both over one’s own body and over life choices. We possess a basic assumption that it is ‘me’ that initiates our own actions and ideas. Stroke challenged this sense of agency for participants. For some participants this related directly to their ability to control their bodily movement. Previous studies have specifically considered agency from this perspective of body intentionality and movement, especially in the context of apraxia (Arntzen & Elstad, 2013; Maurice Merleau-Ponty et al., 2004). Arntzen and Elstad (2013) concluded that where stroke survivors were unable to control their bodily movement, it caused them to also question if they had control over themselves existentially. This results in what has been described as “an unhomelike” being in one’s own body whereby the body is felt as alien but yet the same (Svenaeus, 2000, p.125). This experience was reflected in some of my participants but not all. Like “dys-appearance”
Agency referred not just to stroke survivors’ perception of control of their body and life, but also referred to their sense of place in this world. Thus the embodied experience of stroke was not simply a bodily phenomenon but an existential one as well. This is in part due to tensions between what participants wanted to do and what their body allowed them to do in their everyday life as suggested in previous studies (Bergström, Eriksson, Asaba, Erikson, & Tham, 2015; Kitzmüller et al., 2013; Pallesen, 2014). This more practical and tangible interpretation of agency was prevalent amongst participants. Consequently, regaining the ability to undertake a seemingly simple and relatively minor everyday task could result in significant gains in perceived agency. However, agency also referred to less tangible pondering by participants around the control they had over their own life, and musings about higher meaning such as spirituality and metaphysical existence. Having a stroke appeared to throw participants into an “unreal world” causing them to question previously held assumptions about the world around them. Past studies of stroke survivors have described people experiencing a foreign world after stroke (Bergström et al., 2015; Ellis-Hill et al., 2000). In this unreal or foreign world the body could often “dys-appear” and “become the foreground” (p.248) with the result that stroke survivors’ view of the world narrows (Toombs, 2001). This changed experience of the world due to a new bodily experience, can be transformational in such a way that it as if the person no longer lives in...
the same world (Toombs, 2001). This notion reverberated amongst my participants. Thus having a changed bodily experience can profoundly affect stroke survivors’ experiences and perceptions of the world.

In summary, the relationship between body, self and the world is complex after stroke. Experiencing the body as strange, distant and object-like is common amongst stroke survivors, with a resulting changed awareness and dialogue with their own body. However, this changed relationship between body and self was highly dynamic, being connected with many other psychological factors like self-identity and agency, temporal factors such as transition from hospital, and contextual factors. These contextual factors can influence the embodied experience and will be considered in the following section.

5.5 Influencing the embodied experience

The relationship between stroke survivors’ body and self was dynamic and complex at the time of transitioning from hospital. Accordingly, the embodied experience was impressionable at this time, being in a state of flux. This emphasizes Merleau-Ponty’s (1996) argument that embodiment is not just the relationship between body and mind but also the relationship with the world. This is perhaps the most significant point when considering rehabilitation; the embodied experience stroke survivors have is not absolute, we can influence it for better or for worse.
5.5.1 Importance of context

There is a paradox that is illuminated when stroke survivors leave hospital and find that their bodies do not act as they had expected in familiar situations. This has been suggested to result in a crisis both in terms of body-self dilemmas but also in terms of practicalities which the real world hold (Arntzen et al., 2014; Cott et al., 2007; Luker, Lynch, Bernhardsson, Bennett, & Bernhardt, 2015). My findings suggest there was a clear distinction between hospital and ‘home’, especially for those who had moved into long-term care facilities as a result of their stroke. These findings support the previous understanding that transitioning from hospital is challenging (Cott, 2004; Cott et al., 2007). This has been cited as being due to feelings of abandonment (Ellis-Hill et al., 2009), the challenge of regaining physical function (Wood et al., 2010) and getting back to meaningful roles (Cott et al., 2007; Pringle, Drummond, & McLafferty, 2013; Wood et al., 2010). The tension between stroke survivors perception of their body and self has also been observed in the in-patient setting (Arntzen et al., 2014). However, in this setting Arntzen et al. (2014) observed that this renegotiation was “muted in the professional context” (p.10) which was suggested as a protective mechanism. Participants in my study often spoke of positive experiences of the hospital environment, particularly with rehabilitation staff. The moments which appeared most prominent to my participants were often the small, incidental moments such as a charge nurse chatting about the future, or a physiotherapist telling a person to “just walk”. These moments helped to anchor participants into a more acceptable embodied experience. These moments stood out to participants, perhaps suggesting that discussions regarding stroke survivors’ changed relationship between their body and self were indeed muted as Arntzen et al. (2014) had
suggested. Regardless, this implies that the environment surrounding stroke survivors is not only important but can also be influential for embodiment.

Returning home also prompted stroke survivors to consider what having a changed physical body meant in terms of how they considered (or constructed) their self-identity. This has been described as the “social self-body” (Ellis-Hill et al., 2000, p.730) and refers to how the body is perceived differently when under social gaze. This, for my participants, was related to perceived social stigma of moving differently or being dependent, but also related to the heightened physical awareness of their body when in an unfamiliar environment. Other studies of stroke survivors have suggested that people’s feeling of normality is central to their recovery, to the degree that other people’s reactions could have an effect on stroke survivors perceptions of themselves as ‘normal’ (Kaufman, 1988). This notion was evident amongst my participants with many people minimizing physical restrictions of their stroke, or alternatively being mindful of how their post-stroke body must appear to others. Similarly, participants could experience their body more positively when in the presence of a loved one, compared to with health care professionals. This suggests that the embodied experience of stroke is also socially constructed.

**5.5.2 What helps? Anchors**

My theoretical model of embodiment for people transitioning from hospital after stroke depicts how, further to an individuals’ context, the knowledge and attitude he or she held was also influential. These anchors could be said to help stroke survivors to create coherence in their biographical flow (Faircloth et al., 2004b). Corbin and Strauss (1987)
termed this “biographical accommodation” (p.261) or others have described it as “narrative reconstruction” (Faircloth et al., 2004a, p.84). This terminology suggests reframing or redefining of oneself. However, anchors in the context of my findings also referred to stroke survivors becoming re-familiar with their body, whereby a ‘new normal’ within their body was learnt. Faircloth et al. (2004a) refers to this as “testing the body” (p.78) and Kvigne (2003) describes this as “re-embodiment” (p.1304).

Part of this re-familiarizing allowed my participants to become comfortable again with their body; echoed by Charmaz (1995) where the “sick body” (p.672) becomes familiar and comfortable. This intrinsic knowledge of one’s body and one’s body in relation to the world has been previously cited as being a resource to live with a “vulnerable” and “unreliable” body (Pallesen, 2014, p.235). This idea is similar to Zeiler’s (2010, p.338) terminology of body “eu-appearance” where the once “sick or disabled” body that had “dys-appeared” (Leder, 1990, p.26) can then stand out as “good and easy”, becoming a positive experience. This phenomenon has been described by other authors. For instance, Papadimitriou (2008) described how people using wheelchairs could become “en-wheeled” (p.695) once they were able to view their wheelchair as an extension of themselves, and as a means of allowing body intentionality. Likewise, Gibson (2006) referred to the notion of “decentred subjectivity” (p.194) whereby a person’s sense of self is no longer contained within the physical body, but could positively extend to aids such as wheelchairs. This learning process that people with health conditions, like my participants, have undergone appears to anchor people more satisfactorily in their changed physical body, allowing a more positive embodied experience.
Knowledge, both intrinsic about one’s own body, and general in terms of stroke and anatomy, appeared to improve participants embodied experience. Similarly Thomas and Wardle (2014), who interviewed retired people about their experience of ageing, concluded that people’s understanding of the biopsychosocial nature of their bodies enabled them to maintain their bodies’ dignity and self-worth in spite of created conflicts in body and self through ageing. This positive effect of knowledge on the embodied experience resonated in my findings. Likewise a number of participants spoke positively about participating in physiotherapy and especially exercising. Previous research has found that physical activity can improve peoples’ perceptions of their body (Kitzmüller et al., 2013; Morris, Oliver, Kroll, Joice, & Williams, 2015), which can be considered as a form of “manifestation of selfness” first described by Gadow (1982, p.181). This idea is echoed by Zeiler (2010) who described positive bodily awareness whereby a person can refer to their body as a thematic object without alienation but instead as a well-functioning body with bodily pleasure. Participants in my study spoke of how their body felt good when exercising, despite the effort of the task in hand. Charmaz (1996) discussed the idea of “surrendering” whereby a person stops pushing bodily limits and instead goes intentionally in quest of control over his or her own body. This can be considered as mastery and was often described by my participants. Although mastery often moved participants towards a more cohesive experience of their body and self, the process of mastery has been said to infer objectification of the body (Gadow, 1980). As such, mastery of the object body, where there is accepted divergence between body and self, is viewed by Gadow (1980) as essential for onward the development of a self-body unity.
This supports my findings that knowledge, especially of one’s own body, after stroke can enhance the embodied experience.

Participants’ attitudes also anchored them into a more comfortable embodied experience. This is supported by a systematic review of adjustment studies after stroke, which indicated that personal characteristics such as determination, perseverance, a positive outlook, hope and inner strength, were all important in adjustment (Sarre et al., 2013). Hope in particular was a common thread for my participants and appeared to be helpful in adjusting to their post-stroke embodied experience. Hope is a known motivator and is associated with improved well-being (Bright, Kayes, McCann, & McPherson, 2011). Importantly, it was often the seemingly small things which helped participants to maintain hope such as incidental comments by nursing staff, or a moment with a loved one. This finding is supported by other studies exploring goal setting (Brown et al., 2013) and resilience after stroke (Sarre et al., 2013).

Additionally to hope, attitude also referred to a participant’s personal outlook. Often this referred to what participants described as “being positive”. Positivity overlapped with hope for the future but also presented in people’s interpretation of events such as viewing challenging therapy sessions with optimistic determination. For many participants, this positivity was attributed to a personal trait, for example, being a ‘determined person’. For some participants, having a positive outlook also related to being spiritual, which featured as a source of strength and foundation for these participants in an otherwise unreal and unfamiliar bodily experience. Similarly Faircloth et al. (2004b)
observed how some stroke survivors bolstered acceptance of their bodies’ limitations by referring to a transcendent purpose. These traits are acknowledged in the field of positive psychology, being listed as character strength and virtues (Peterson & Seligman, 2004). Thus these are not new ideas about personal attributes being important in people’s experience after stroke. However, what is illuminated is that these personal attributes are significant in people’s interpretation of their bodily experience after stroke, a notion which has historically been understated in stroke research.

Although many participants spoke of the challenges of their embodied experience, some participants alluded to a sense of personal-growth from their stroke. For instance, the stroke had crystallized what was important for some participants for which they were grateful. This can be considered as resilience. Resilience, like many psychological concepts, is an evolving paradigm. To date there are no consensus definitions for resilience but it is generally accepted as a positive adaptation despite experiencing adversity (Herrman et al., 2011). The body can be considered as central to resilience and yet is under-acknowledged in the resilience literature (Sarre et al., 2013) despite empirical evidence that the body is significant in relation to what makes a ‘good’ life, especially in terms of health (Aranda, Zeeman, Scholes, & Morales, 2012). Resilience can be viewed as dynamic, being both found within personal attributes, and made from external assets, such as societal interpretation of health problems (Aranda et al., 2012). Although the term resilience often refers to positive transformation, it has also been conceptualized as encompassing seemingly negative responses, which serve to protect the individual (Lepore & Revenson, 2006). Thus resilience does not mean either bouncing back or learning to
live in a situation of ongoing risk (Sarre et al., 2013). Instead there is not such a
dichotomy, and both of these things can occur concurrently (Sarre et al., 2013). This was
apparent amongst my participants, with ‘anchors’ sometimes emphasizing the divergence
in an individual’s embodied experience, and yet enabling them to feel more at ease and
accepting of their post-stroke body.

In summary, contextual, temporal and intrinsic anchors such as knowledge and
attitude can be considered as helpful for stroke survivors in their embodied experience.
This affirms previous findings that personal, social and psychological factors (World
Health Organization, 2001) are significant in health. However, it should be emphasized
that personal, social and psychological factors are also highly influential on how people
experience their body after stroke.

5.6 **The embodied experience as central to stroke physiotherapy**

The embodied experience of stroke clearly extends beyond the physical body, and
yet embodiment remains tacit and hidden in physiotherapy practice and models. Thus
there appears to be a discrepancy between theoretical models of physiotherapy and the
practice context of chronic conditions such as stroke. Furthermore, it is plausible that there
is also a discrepancy between what physiotherapists perceive their rehabilitation approach
to be and what they deliver.
5.6.1 Embodiment and current physiotherapy approaches

Physiotherapy practice has been criticised for its lack of theory and theory development in relation to embodiment (Cott et al., 1995; Nicholls & Gibson, 2010) and hyper-focus on physical function (Nicholls & Gibson, 2010; Sarre et al., 2013). The most predominant framework for thinking about physiotherapy practice is the World Health Organisation’s International Classification of Functioning, Disability and Health (ICF) which acknowledges the multi-faceted nature of health, including personal and social factors (World Health Organization, 2001). The ICF attempted to combine concepts from the biopsychosocial model of health conditions, and disability models, to create an encompassing model (Sampaio & Luz, 2009). Superficially, it may seem that the ICF acknowledges the embodied experience in health conditions. However, the ICF continues to compartmentalize people’s experiences of health and disability. In particular the ICF has been denounced for failing to acknowledge potential differing perspectives of the individual compared to the perspective of external observers, such as health care professionals (Wade & Halligan, 2003). Additionally the ICF model fails to consider temporal factors such as the individual's stage of life and phase of health condition (Wade & Halligan, 2003), and as such does not acknowledge transitory periods like that in my study. Finally, the ICF is embedded with ontological assumptions of a pre-social, neutral body (Sampaio & Luz, 2009) which fails to consider the complexities of embodiment. My study highlights the tensions between body and self in the embodied experience of stroke. Thus it is possible that health care professionals, like physiotherapists, may wrongly make assumptions about a stroke survivor’s bodily experience.
Some theoretical pieces about physiotherapy practice have attempted to address this void and explore a more multi-dimensional view of the body. For example, Wikström-Grotell and Eriksson (2012) discussed the concept of movement in physiotherapy, emphasizing the need for a more multi-dimensional understanding of movement instead of the historically biomedical focus. This perspective was founded on the observation that theory-building in physiotherapy has been underpinned by a positivist paradigm, with a lack of philosophical questions being asked by the profession (Wikström-Grotell & Eriksson, 2012). Movement is often quoted as the common denominator for physiotherapists, with practices being stated to develop, maintain and restore people’s maximum movement (World Confederation for Physical Therapy, 2014). The Movement Continuum Theory of Physical Therapy developed by Cott et al. (1995) attempts to rectify the lack of theoretical evolution of physiotherapy by providing a theory of how physiotherapists conceptualize movement, and approach clinical practice. However, there has been little development or acknowledgement of the Movement Continuum Theory (Cott & Finch, 2007), and movement remains to be considered at a biomechanical level by physiotherapists, rather than as an embodied phenomenon.

Physiotherapists aren’t alone in fragmenting people’s bodies when working with people after stroke (Bendz, 2003) but given the increasing weight of evidence that more integrated, person-centred ways of working with people after stroke are better received and more meaningful, a reframing of practice is necessary. My research study supports this need by illustrating that the body is more than ‘a machine’ and yet interventions utilized by
stroke physiotherapists do not commonly account for the body beyond biomechanical aspects.

A few studies have attempted to better understand the concept of the body in clinical practice for physiotherapists. For example, Jorgensen (2000) explored the concept of the body and health specifically in physiotherapy by conducting semi-structured interviews, and observing physiotherapists with orthopaedic patients (Jorgensen, 2000). They concluded that despite physiotherapists believing they took a ‘holistic’ approach, their practice reflected a very physical and instrumental concept of the body focusing on attainment of functional tasks and overlooking patients’ interests, roles, experiences and expectations. Similarly, interviews with stroke survivors, their carers and physiotherapists regarding physical activity indicated disparate priorities (Morris et al., 2015). For stroke survivors and their carers, physical activity contributed to them regaining their physical and social sense of self, both of which were related to self-efficacy. Conversely, physiotherapists tended to take a biomedical perspective of physical activity, perceiving that stroke survivors had little control over their outcome, and focusing very little on life-enhancing activities (Morris et al., 2015). These findings are reverberated in an autoethnographic piece exploring person-centred practice in physiotherapy, which considered how the biomechanical discourse that historically has underpinned physiotherapy is preventing evolution away from a mind-body split and paternalistic approach (Mudge et al., 2013). Thus there is growing endorsement for theoretical conceptualization of the embodied experience of health.
Person-centredness is commonly believed as important in rehabilitation (Gzil et al., 2007) especially for stroke rehabilitation during the transition home (Luker et al., 2015; Salter et al., 2008; Yeung, Wong, & Mok, 2011) and is advocated as part of physiotherapy (Mudge et al., 2013). The term ‘person-centredness’, also termed patient- or client-centredness, has been utilized by a number of professions with differing interpretations. Patient-centredness emerged from psychologist Carl Rodgers underpinned by humanist philosophy (Kirschenbaum & Jourdan, 2005). In physiotherapy practice person-centredness is considered as including shared decision making, consideration of individuals’ context, and showing respect (Lepege et al. 2007). The term person-centredness has become increasingly prevalent in stroke rehabilitation research, guidelines and institution policies (Gzil et al., 2007). For instance, the New Zealand Stroke Guidelines state “rehabilitation is a proactive, person-centred and goal-orientated process” (Stroke Foundation of New Zealand & New Zealand Guidelines Group, 2010, p.44). Similarly in the context of stroke survivors returning home a number of studies allude to services needing to adopt a person-centred approach (Salter et al., 2008; Yeung et al., 2011). However, given the term person-centredness is interpreted differently by professions the reality of what person-centredness actually means practically can be elusive (Teasell, 2011).

Physiotherapy practitioners being interviewed have perceived their practice as person-centred believing that they gave control to their patients (Beeston & Simons, 1996; Bendz, 2000). However a disparity remains between what health care professionals think they deliver and what they actually do, with a tendency for health care professionals to take
a biomedical approach and for patients to remain passive in their rehabilitation (Bendz, 2000). There remains an assumption of a physical body with the concept of the body already being fully established within an individual. However, the embodied self, which encompasses the self, must acknowledge that as beings we are continually developing reality and meaning; thus the body is infinite (Gadow, 1980). This flux in relationship and meaning of one’s body and self was prevalent in my findings.

Explicit components of person-centredness have been identified in previous literature. For instance Cott (2004) attempted to better explain what person-centredness means in practice by identifying the important components of person-centredness from the perspective of adults with long-term physical disability (Cott, 2004). Individualisation of treatment and education to aid decision making were amongst the identified themes. Cott (2004) concluded that person-centredness is a philosophy. This is mirrored by Hammell (2011) who suggests person-centredness is fundamentally about the locus of control and suggests that clinicians should view themselves as a resource which clients can utilize (Hammell, 2001). For physiotherapists to be able to be an individualised ‘resource’ for stroke survivors and deliver person-centred care, they need to have an understanding of each person’s individual experience of stroke and transitioning from hospital with a changed body. Therefore a first-person conception of the body has been advocated to encourage physiotherapists to look beyond the biomechanical body that predominates frameworks of physiotherapy (Sivertsen & Normann, 2014)
Prior to undertaking this research study I believed I was person-centred in my practice. However, in my undergraduate training and clinical practice I was oblivious to the notion of embodiment. I believed there was instead a gap in the existing literature. Having explored deeper into research of the embodied experience of stroke, I have realized there is in fact a wealth of research on this topic. This has made me question why I was so unaware of what seems now like an obvious experience for stroke survivors to have. Is it that I did not see the existing literature on the topic clearly? I believe that my training had not steered me to consider more holistic and qualitative research studies exploring the stroke experience. Instead I was directed to quantitative studies of biomechanics and objective measurements of stroke, with perhaps a token mention of utilizing a holistic approach. Despite there being extensive evidence that health care professionals need to take a ‘whole person’ approach to stroke rehabilitation, there appears to still be a biomechanical bias in our reading, research and teaching.

Arguably consideration of psychosocial aspects of health are already considered within the scope of physiotherapy given it is listed in our professional competencies (Physiotherapy Board of New Zealand, 2008; World Confederation for Physical Therapy, 2012). However, it appears that physiotherapists need to extend their scope of ‘typical’ practice to include an overt consideration of psychosocial aspects of health as well as the biomedical. Is there a risk of physiotherapists dabbling into psychological aspects of stroke such as hope and self-identity? I believe the answer is no, based on my research findings. Rather, there is a need for physiotherapists to live up to the scope we already identify for ourselves as a profession but do not fulfil. This may be due to physiotherapists
feeling inadequately trained to deal with psychosocial aspects of health, or perhaps being unaware of the biomedical bias in clinical practice (Thornquist, 1994). The next section will outline how I believe this can be achieved through my research experience.

5.6.2 A different approach? Implications for practice

My research findings indicate there is a need to recognize that the embodied experience can flux, being impressionable, at least at the time of transition from hospital to home. Clinicians should not underestimate the significance of this fundamental disruption in body and self. In particular for health care professionals, especially physiotherapists, there is a need to acknowledge the psychological aspects of living with a changed body after stroke, and be able to work in better partnerships with patients so as to maximize their unique recovery experience.

Although my research study did not specifically explore the relationship between stroke survivors and health care professionals in the embodied experience, my findings in conjunction with previous research indicate that this relationship is an important aspect of the anchoring environment surrounding stroke survivors. For instance, Arntzen et al. (2014) suggested that health care professionals approached changed bodies after stroke in a narrow way which prompted stroke survivors to take a mechanistic view of their own body. Objectifying and devaluing the body in this way may result in a divergence in oneself which, at worst could prompt an existential crisis associated with mental health problems (Bandura, 1977). Instead, “psychological processes of identity preservation and social affiliation” are argued to be crucial in making sense of one’s changing body
(Thomas & Wardle, 2014, p.20). Consequently, there is a need for physiotherapists to be able to understand the psychological adjustments to a changed body after stroke, recognizing these can be influenced and then reflecting this in clinical practice.

Physiotherapists are in a powerful position of influence in terms of stroke survivor’s embodied experience. Participants in this study described how their experiences with health care professionals was less about what the content of therapy was, but more about how it was delivered. For example, George revelled in the experience of “free” walking when his physiotherapists prompted him to just embrace the task in hand. This created a more positive bodily experience. One component of person-centred care therefore should include a broad view of the body, with respect for the persons’ experiential and bodily knowledge (Pallesen, 2014; Sivertsen & Normann, 2014). This means promoting stroke survivors as experts in their own bodies and nurturing mastery. This overlaps with the notion of “embodied intelligence” which can be described as the body itself being “knower and interpreter” (Price, 1993a, p.40). Embodied intelligence relies of a degree of body listening, which my participants described. Body listening may be done at any time but appeared more likely to increase when stroke survivors experienced a situation involving physical change. This has been echoed in people with other chronic health conditions like diabetes, multiple sclerosis and asthma, as well as healthy individuals (Price, 1993a,b) with body listening being described as both inherent, as in “embodied intelligence”, or as a learned phenomenon. Body listening is important because it provides meaning for people of their physical experience, whereby in the presence of disease people can learn a new body paradigm. Price (1993a) argued this
awareness can be developed to enhance practical knowledge such as how to manage fatigue. Furthermore this recognition of stroke survivors being experts in their own bodies empowers and promotes a person-first approach to stroke rehabilitation (Harrison & Williams, 2000; Jones, Mandy, & Partridge, 2000; Luker et al., 2015; Sivertsen & Normann, 2014).

In addition to facilitating stroke survivor’s awareness of their own body in order to learn a new body paradigm, physiotherapists need to be able to support stroke survivors in creating new strategies and redefining themselves. Rehabilitation must ultimately have its goal as opening up new horizons so that stroke survivors do not ‘become stroke’. Consequently successful rehabilitation should mean that the lived body has been restored to a harmonious state whereby the stroke survivor can once again move freely along the mind-body-world continuum (Pallesen et al., 2014). At times this will mean “illness-in-the-foreground” where a divergence in body and self is prevalent, but at other times will emphasize “wellness-in-the-foreground”, both terms being described by Pallesen et al. (2014, p.240). This can be considered as adjustment.

In the context of adjustment, two types of coping strategies have been described; “problem-focused” and “emotion-focused” (Sarre et al., 2013, p.721). Some of the practical strategies could be considered as the essence of physiotherapy practice, such as relearning skills, exercising, taking risks to achieve an activity and making modifications to activities. These practical strategies, including physical activity, have been shown to aid restoration of a physical and social sense of self (Morris et al., 2015). However, the more
emotion or cognitive focused forms of coping like redefining core ideas of self, re-evaluating norms and values, and re-evaluating reality (Sarre et al., 2013), are currently not considered as being within the scope of physiotherapy practice (Gard & Gyllensten, 2000). Furthermore, there appears to be a gap in what physiotherapists believe they deliver in terms of psychological consideration and what patients feel they receive (Harrison & Williams, 2000) as well as what psychological factors physiotherapists believe can be influenced (Morris & Williams, 2009). This suggests there is a lack of understanding of the psychological aspects of stroke as well as clinicians insights into their own practice (Gyllensten, Gard, Salford, & Ekdahl, 1999; Harrison & Williams, 2000; Klaber Moffett & Richardson, 1997). Thus physiotherapist training should develop skills to better understand and support stroke survivors with the psychological factors underlying their embodied experience.

A further significant component of psychological adjustments identified in the embodied experience was hope. Hope is complex, multi-dimensional and can be influenced (Bright et al., 2011). Furthermore, hope has been associated with positive outcomes for stroke survivors (Bright et al., 2011). This suggests that if physiotherapists were comfortable and able to acknowledge fear, low mood, self-identity as well as ‘anchors’ like hope, personality traits and resilience, physiotherapists may be better able to instil a sense of a positive future for stroke survivors, regardless of anticipated physical recovery.
The question of how this can be achieved extends beyond the scope of this current study. However, I do have some recommendations for practice based on my experiences through undertaking this study and which perhaps form the basis of future research questions (see ‘Recommendations for future research’):

1) Taking time to listen. The process of allowing people to speak openly and for me to listen attentively during interviews has been liberating for me. Though I believed I asked open questions in my practice prior to this research, I realize on reflection my agenda prevailed in these interactions. For example, wanting to focus on providing exercises, or getting through my assessment questions. Conversely, during study interviews I gained rich information and insight into people’s bodily experience of stroke, which could have been used to guide rehabilitation had I been their treating physiotherapist. Similarly, the process of taking time to listen also prompted reflection in my practice. I have since noticed and started discussions with my patients on their comments of a changed body, which has led to honest and reflective discussions about people’s sense of body and self after stroke. I believe these discussions have been an enriching experience for both me and my patients. With this in mind, I believe as undergraduates and as practitioners it is a valuable experience to speak openly with stroke survivors about their experience. This should be without a ‘physiotherapist agenda’ but instead as person to person, sharing an individual experience. This recommendation has been conveyed by other clinicians who have undertaken qualitative research and found that it promoted attentive listening for them (Bright, Boland, Rutherford, Kayes, & McPherson, 2012).
2) Enhanced inter-professional working both in clinical practice and in research. Softening the boundaries between health care professionals could enable the embodied experience of stroke to be considered more wholly rather than compartmentalizing people after stroke. This needs to occur in our discipline-specific models, clinical practice and amongst research literature. There is a wealth of knowledge and understanding amongst health care professionals and this could be better shared.

3) Mastery and mindfulness. The process of promoting people as experts in their own bodies appeared helpful both in terms of empowering and mastery. This notion overlaps with the idea of mindfulness which is “the intentional, accepting and non-judgemental focus of one's attention on the emotions, thoughts and sensations occurring in the present moment” (Zgierska et al., 2009, p.267). Thus facilitating mastery and mindfulness in rehabilitation such as physiotherapy practice could enhance the embodied experience for stroke survivors.

5.7 Limitations

Whilst this study has contributed to the understanding of the embodied experience of stroke, particularly when transitioning from hospital, there were some limitations to the study which need to be acknowledged. Firstly some experiences associated with embodiment might be difficult if not impossible to explain, especially in the presence of impairments of interoception. This inexplicability was, in itself, a finding of this study in some regards, however other methods based more heavily on observational data collection such as combining interviews with observation of performance of functional activities
might help shed further light on the topic of embodiment after stroke in a way that grounded theory based solely on interviews cannot.

Furthermore, the small number of participants meant that some important factors in the embodied experience may not have been considered. Although the focus of this study was depth of understanding regarding embodiment, rather than breadth, there may be additional influencing factors which were not considered for people after stroke. For instance, all participants were of New Zealand European descent, with no Māori participants included in the sample. Culture may be important in a person’s embodied experience of stroke (Wilde, 1999) which may have not been evident amongst my relatively culturally homogenous participants. Similarly, participants were all over the age of 65, reflecting the characteristics of the people who utilize the service I worked in. However, age and stage of life has been suggested as important in the embodied experience (Faircloth et al., 2004a; Thomas & Wardle, 2014). A further possibly significant factor in the embodied experience is gender differences. There were two women and five men in this study and no specific gender differences of the embodied experience were apparent from the data. However, a number of previous studies have suggested there may be unique embodied experiences for each gender (Charmaz, 1995; Clarke & Griffin, 2008; Murray & Harrison, 2004). Therefore the small sample size may have narrowed my interpretation of the embodied experience of stroke.

A further limitation was the temporally isolated view of participants’ embodied experience. Participants were interviewed for data collection on one occasion to capture
the transition phase after hospital. Although phone calls were made to rapport-build and capture experiences over the first month after leaving hospital, only a ‘snapshot’ was gained of their embodied experience with one formal interview. It may be useful to know how people’s embodied experience change over time after transitioning from hospital after stroke by interviewing people again at a later time after their return home. For instance, issues of identity have been described at one year after stroke (Ellis-Hill et al., 2000) but appear to be mostly resolved, or at least accepted by five years after stroke (Pallesen, 2014). However, previous research focuses on just some components of the embodied experience such as identity and coping, over time, presenting a gap in understanding. These limitations could be addressed in future research to more fully understand the embodied experience of stroke.

5.8 Recommendations for future research

Understanding the embodied experience of stroke, especially within physiotherapy, is in its early stages. This study has highlighted a number of questions that require further investigation including the effect health care professionals have on a person’s embodied experience, augmenting interactions that may enhance a person’s embodied experience after stroke, and consideration of physiotherapy scope of practice regarding embodiment. Firstly, given the small size and relatively narrow inclusion criteria for my study, it would be worthwhile gathering data on the embodied experience on a wider population such as younger people, differing cultural backgrounds and other health conditions.
To better understand how health care professionals can enhance stroke survivors' bodily experience we need tailored tools to measure this area of work. Given the importance highlighted by stroke survivors of their sense of self in the experience of their physical body, it is essential that we can measure self-concept more effectively. Currently research attempting to measure how rehabilitation influences psychological factors utilizes measures of health related quality of life (Levack et al., 2014). However, self-concept is distinct from quality of life and it is possible for a person to have a strong self-concept and yet a numerically low quality of life according to rating scales (Levack et al., 2014). Therefore a robust measure of self-concept, which could be utilized to better capture embodied experiences, is an important first step.

Similarly, the significance of psychological factors in the experience of the physical body has been illuminated by this study. This suggests that there is a need for stronger collaboration between physiotherapists and psychologists to enable a more holistic approach to care. This is especially pertinent given a documented shortage of psychological services for stroke care (Rodgers, Dennis, Cohen, & Rudd, 2003) and anecdotally limited access to psychologists in the services I have worked in. Research focused on this collaborative practice and development of specific approaches physiotherapists can adopt which better encompass the psychological nature of the embodied experience would therefore be paramount.

Additionally, further to my recommendation of physiotherapists developing their communication skills to better understand the embodied experience of stroke, research
focused on the effectiveness of interventions targeting communication skills would be valuable. Although research has been conducted considering clinicians engagement with patients (Bright, Kayes, Worrall, & McPherson, 2014), there is no research regarding the effect of engagement between clinicians and people’s embodied experience of health conditions.

Finally, theoretical papers regarding physiotherapy scope of practice need to be undertaken to enable comprehensive theoretical foundations from which the profession can evolve. Proposals of alternative models for physiotherapy practice have been suggested (Cott et al., 1995; Siegert, Ward, Levack, & McPherson, 2007). However these models remain suggestions and further research is required to find widely acceptable models for the physiotherapy profession. This would enable physiotherapists to better define and develop their practice beyond a biomechanical view of the body.
Chapter 6: Conclusion

This thesis has explored the embodied experience of stroke when people leave hospital and offers one explanatory theory to describe the dynamic relationship between a stroke survivors’ sense of body and self. Stroke survivors in this study, one month after discharge from hospital, experienced a state of flux between a sense of their body and self being divergent versus cohesive. This experience related to the familiarity of people’s own bodies after stroke, and the alignment of their bodily perception compared to their perception of themselves. The embodied experience of stroke has been shown to extend far beyond the physical body, with people’s bodily experience influencing their perception of themselves, and their perception of themselves influencing their experience of their body. This suggests that the rehabilitation of the physical body should not be considered in isolation after stroke.

Furthermore, stroke survivor’s embodied experience can be influenced by their knowledge, attitude and the environment around them. This is significant for models of rehabilitation, especially physiotherapy whose professional practice is centred on the physical body. Stroke rehabilitation may be enhanced by better understanding and integration of embodiment theory into models of care. Future research should therefore focus on how physiotherapists can develop and fulfil their scope of practice to encompass people’s entire bodily experience after stroke.

Finally, this research thesis has highlighted the value of experiential learning for me. I believe that the insights I have gained, on reflection, were actually already mostly
embedded in existing other professions research. However, through the process of interviewing participants and reflective practice, I feel I have gone through a learning process whereby I am now ‘knowing differently’. This understanding I have gained has broadened my view and enabled me to appreciate more fully people’s experiences after stroke. It may be possible to harness this experiential learning process for other physiotherapists to further enhance delivery of care for stroke survivors. Future research considering both theoretical models of practice and skills sets for physiotherapists would therefore be paramount. It has been a privilege to undertake this research journey which has empowered me to consider what it means to be ‘some (body) else’ after stroke.
Glossary

**Constant comparative method:** A method of analysis that generate successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category, and category with concept. Comparisons then constitute each stage of analytic development (Charmaz, 2006, p. 187).

**Constructivism:** An epistemology that ‘truth, or meaning, comes into existence in and out of our engagement with the realities in our world’ (Crotty, 1998, p. 8).

**Credibility:** A criteria for against which a grounded theory study can be critically evaluated. Credibility refers to how believable the research process, data analysis and breadth of the final theory is (Charmaz, 2006).

**Data saturation:** A grounded theory term referring to a point during analysis when the collection of further data is unlikely to reveal any new direction, any new questions or any reason to sample data further (Charmaz, 2006).

**Embodiment:** Embodiment can be defined as “how we live in and experience the world through our bodies” (Merleau-Ponty, 1962 as cited by Wilde, 1999, p.27).

**Epistemology:** The study of knowledge. Epistemology relates to one’s beliefs regarding the nature of knowledge and how it is possible to know what we know. (Crotty, 1998).
Objectivism: An epistemological position that ‘things exist as meaningful entities independent of consciousness and experience, that they have truth and meaning residing in them as objects and that careful research can attain that objective truth and meaning. This is the epistemology underpinning the positivist stance.’ (Crotty, 1998, p. 5-6)

Ontology: The study of being and existence. Ontology relates to how one perceives the nature and structure of reality, and in social science, the nature and structure of social reality (Crotty, 1998).

Originality: A criteria for against which a grounded theory study can be critically evaluated. Originality refers to how novel the work resulting from a grounded theory study is. Originality can be judged on the basis of whether it produces new perspectives, as opposed to being a re-packaging of pre-established concepts (Charmaz, 2006).

Positivism: An epistemology that subscribes to a unitary scientific method consisting of objective systematic observation and experimentation in an external world. The goal of positivistic inquiry is to discover and to establish general laws that explain the studied phenomena and from which predictions can be made. Subsequently, experimentation and prediction can lead to scientific control over the studied phenomena. (Charmaz, 2006, p.188)

Purposeful sampling: An approach to selection of participants or sources of data on the basis of their characteristics. Purposeful sampling is most often used at the beginning of a
grounded theory investigation in order to ensure a wide range alternative perspectives are represented in the data for analysis. However it is replaced by theoretical sampling as a study progresses (Charmaz, 2006).

**Realism:** An ontological perspective that assumes a ‘real’ reality exists, and that this reality exists outside the conscious mind (Crotty, 1998). Realism can be contrasted with the ontological perspectives of ‘idealism’: the worldview that reality is solely a product of the mind and ideas (Crotty, 1998).

**Rehabilitation:** A ‘process aimed at enabling persons with disabilities to reach and maintain their optimum physical, sensory, intellectual, psychiatric and/or social functional levels, thus providing them with the tools to change their lives towards a higher level of independence.’ (World Health Organisation, 2001, p. 290)

**Relativism:** An ontological position that what is said to be reality is really just ‘the sense we make of them’ (Crotty, 1998, p. 64). This perspective assumes that ‘different people may well inhabit quite different worlds’ (Crotty, 1998, p. 64). Symbolic interactionism, the theoretical perspective underlying grounded theory, has been said to require relativist ontology. (Crotty, 1998).

**Resonance:** A criteria for against which a grounded theory study can be critically evaluated. Resonance relates to the degree with which a study is meaningful to people or
situations outside the immediate scope of the lives of the individual people who participated in the study (Charmaz, 2006).

**Stroke:** An ‘abnormal condition of the brain, characterised by occlusion by an embolus, thrombus, or cerebrovascular haemorrhage or vasospasm, resulting in ischemia of the brain tissues normally perfused by the damaged vessels’ (Harris et al., 2006, p. 330). Stroke is also known as a ‘cerebrovascular accident’.

**Subjectivism:** An epistemological position that the nature and existence of reality (and all objects in reality) is solely the product of the subjective experience. Crotty (1998) made this distinction between subjectivism and constructionism: In constructionism, meaning is created from the interaction between conscious beings and things in the world, whereas in subjectivism, meaning is create independent of the things in the world and imposed on reality.

**Symbolic interactionism:** A theoretical perspective derived from pragmatism which assumes that people construct selves, society, and reality through interaction. Because this perspective focuses on dynamic relationship between meaning and actions, it addresses the active processes through which people create and mediate meanings. Meanings arise out of actions, and in turn influence actions. This perspective assumes that individuals are active, creative, and reflective and that social life consists of processes. (Charmaz, 2006, p. 189)
**Theoretical perspective:** The ‘philosophical stance informing the methodology and thus providing a context for the process and grounding its logic and criteria’ (Crotty, 1998, p3).

**Theoretical sampling:** A type of grounded theory sampling in which the researcher aims to develop the properties of his or her developing categorise or theory, not to sample randomly selected populations or to sample representative distributions of a particular population. When engaging in theoretical sampling, the researcher seeks people, events, or information to illuminate and define the boundaries and relevance of the categories. Because the purpose of theoretical sampling is to sample to develop the theoretical categories, conducting it can take the research across substantive areas. (Charmaz, 2006, p. 189)

**Usefulness:** A criteria for against which a grounded theory study can be critically evaluated. Usefulness related to the utility of the analysis arising from a study and its interpretations, its applicability to further research, or other non-scientific contexts (Charmaz, 2006).
References


Appendix 1

Understanding life in a changed body after stroke

What? A qualitative study being completed as part of my Masters studies.

Who? People who have had:
- First time stroke
- Self-identified significant change in physical ability post-stroke
- Able to communicate effectively via phone in English
- Medically stable
- Able to provide written consent to participate in study
- Live in the Greater Christchurch area

What’s involved? 4 phone calls on returning home and 1 face to face meeting. This will be talking about their experience of living with a changed body after their stroke. Participation is entirely optional and will not affect their usual care.

How?
- Ask potential participants if they are interested in taking part
- If they are, give them the ‘participant information sheet’
- Also contact me with their name and anticipated discharge date
- I will meet any potential participants on the ward and answer any questions

Thank you!!

Emily Timothy
Extension: 68938
Email: emily.timothy@cdhb.health.nz
Appendix 2

Participant Information Sheet

Research title: Embodiment in the transition to life after stroke: An Exploratory Study

Lay title: Understanding life in a changed body after stroke

Invitation

Kia ora, talofa lava and hello, you are invited to take part in a study aiming to explore the experience that people have of living in their body after a stroke. Please remember that:

- Your participation in this study is voluntary (your choice). You do not have to take part in this study
- If you do agree to take part, you are free to withdraw at any time, without having to give a reason. This will in no way affect your current or future health care
- Participation in this study will be stopped should any concerns to your health arise or if your doctor feels it is not in your best interests to continue

This information sheet will explain the research study. Please feel free to ask about anything you do not understand.

What is the purpose of the study?

This study aims to improve physiotherapists’ understanding of the experience of returning to physical activity after a stroke. We want to know:

- What it feels like to have had a stroke
- What it means to have an altered body when you return to activities at home
- What having an altered body means for you

This project is being undertaken as part of the requirements for the principal investigators’ Postgraduate Masters of Health Science.
How are people chosen to be asked to be part of the study?
People are being invited to participate in the research study if they meet all the following criteria:

- Have had a first-ever stroke causing a limitation in physical ability
- Under the care of Canterbury District Health Board (CDHB) Older Persons Health Specialist Services
- Able to communicate in English on the phone (with or without assistive technology)
- People may be excluded from taking part in the study if they are considered very medically unwell.

Potential participants who meet the study criteria will be approached during their hospital stay and invited to take part. Names of interested participants will be passed on to the principal investigator who will then meet participants on the ward to answer questions and explain the project in more detail. Up to 10 people will participate in the study.

What happens in the study?

Should you agree to take part in this project, you will;

- Be phoned once a week when you return home for the first 4 weeks. You will be asked briefly about your physical activity and your feelings on your body that week. This discussion will be audio-recorded for future reference.
- Be interviewed about one month after you return home in a location of your choice. You will be asked in more detail about your experience of physical activity and this will last up to 1 and a half hours. This interview will be audio-recorded so that the discussion can be accurately recorded.
- At the end of the study a summary of the research findings will be sent to you if you wish.

Please note: The aim of the discussions is not to change what you are doing, but to instead explore your experience. The interviewer will not be there to provide you with advice or answer questions regarding your health and may direct you to your GP if required. You may be receiving help from other services at this time and you should continue with their recommendations.

Examples of some of the questions you may be asked are;

1) Tell me what it felt like when you had your stroke

2) Tell me about your experience of returning home
3) What has it been like returning to physical activity since your return home?

If you feel uncomfortable with any of the questions you may decline to answer and you may also withdraw from the project at any stage without any disadvantage to yourself of any kind.

All discussions will be considered confidential but if there are any issues arising during the study that raise concerns about your safety or the safety of others, I will let you know that I will contact your GP, or an emergency health service, about these issues.

You are welcome to have a support person from your whānau or family present to offer encouragement and support at any point during the study.

What information will be collected and what will be done with it?

On the first meeting whilst you are in hospital we will collect some basic information about you including your contact details, ethnicity and a bit about what you are able to do for yourself at that time. Once you return home all our discussions will be audio-recorded. Our discussion will be written down from the recordings and be used by the researcher to determine any common themes that arise for all participants. Information that could identify you personally (such as names of specific people, places or health services) will be deleted from the written notes of these recording.

The information from this study will be used to improve our understanding of what the experience of recovery following stroke is actually like for people who have gone through rehabilitation and left hospital, with the main focus being on their experiences of body function and returning to physical activity after stroke. The themes emerging from the study will be used to improve physiotherapy services for people after stroke.

The researcher will have access to all information which will be securely stored for the duration of the study. Specific identifying personal information will not be presented or shared beyond the student and her supervisors. All information will be destroyed by the principal researcher at the end of the project except that, as required by the University's research policy, any ‘raw’, (initial) non identifying data on which the results of the project depend will be retained in secure storage for ten years, after which it will be destroyed.

The results of the project may be published in a professional journal and will be available in the University of Otago Library (Dunedin, New Zealand). Participants will be invited to see the results of the study if they wish.
What are the benefits of taking part?
This study aims to improve our understanding of your experience of having a stroke. Your contribution will aid the development of future physiotherapy services for people who have had a stroke.

What are the risks of taking part?
There are no increased risks to you beyond the risks of everyday life. There will also be no costs for you to take part. You will just be asked to provide your time. You may withdraw from the project at any stage without any disadvantage to yourself of any kind. Participation will not affect the level of services you currently receive.

Seeking Cultural Support:
The researchers acknowledge the importance of spiritual health (Taha wairua), mental health (Taha hinengaro), family health (Taha whanau) and physical health (Taha tinana) in a person’s overall health and wellbeing. To ensure cultural safety we welcome the inclusion of support from Kaumatua or Whaea for those of you who wish to have this support.

What if I have any questions?
If you have any questions about our project, either now or in the future, please feel free to contact either:-
Emily Timothy and/or Dr Fi Graham
Physiotherapist Senior Lecturer in Rehabilitation
Princess Margaret Hospital University of Otago (Wellington)
Email: emily.timothy@cdhb.health.nz Email: fi.graham@otago.ac.nz
Phone: 03 3378938 Phone: 03 338 3217

This study has been approved by the University of Otago, Wellington School of Medicine. If you have any concerns about the ethical conduct of the research you may contact the Ethics Committee administrator on 03 479-8256. Any issues you raise with them will be treated in confidence and investigated and you will be informed of the outcome.
Appendix 3

PHONE RECORDING SHEET
(Summary only)

Name:
Date:
Week number since discharge:

1) How has your week been overall?

2) What have you been doing?

3) Has anything surprised you in terms of getting back to your usual activities/routines?

4) How do you feel about how your body has managed with your usual activities/routines?

Other comments
INITIAL QUESTIONS FOR INTERVIEWS
Thank you for your time and willingness to participate

Introduction
- As a physiotherapist I have an understanding of the ‘science’ behind strokes but obviously I have no experience of actually having a stroke. Today I am trying to get an understanding of what it feels like from these questions.
- From our phone conversations over the past few weeks you’ve mentioned....

General questions
1) Please could you tell me about any other activities you have tried since leaving hospital that we have not already discussed?
   - day to day tasks
   - recommended exercise/activity
   - leisure pursuits
   - roles
   - community

2) Can you tell me about your experience of returning home generally please?
   - Challenges
   - Feelings
   - positives
   - impact of family/friends/general community

Questions about bodily experiences
1. Please could you tell me what the experience of having a stroke was like?
   - Where were you?
• What sensations went through your body?
• What went through your mind?

2. And could you tell me what it is like to physically recover from a stroke please?
• Could you tell me about any unusual sensations you’ve experienced
• How would you describe the experience of trying to move your LEFT/RIGHT arm/leg
• What does it feel like in your body when you trying to do exercises?
• What do these sensations make you think? About your body? About your recovery?)
  •
• Would you mind telling me how you feel about your body in general after your stroke?
  • How do you feel about your body in the presence of family, friends, and strangers?
  • Do you feel you have a changed image of your body in your mind?
  • What do you think has been the impact of a having changed physical body?

Exit
Is there anything else about your experience of stroke that you’d like to share with me?

Thank you for so much for your time today. Would you like to receive a summary of my findings once I have completed the study? This will likely be mid-2014.
Appendix 5

Understanding life in a changed body after stroke

Summary of findings

I spoke with a total of seven people one month after leaving hospital, after having a stroke. We discussed what it felt like to have a changed body and what this meant for to people. This is a summary of the main experiences that people had at the time of our discussion. The most common experience people described was a back and forth between a feeling of having a separate, strange body, through to a sense that despite the changes to the body, ‘it’s all me’.

‘This body and me’
Many people I spoke to described how their body had become strange, unpredictable and effortful to them. This affected what people were able to do but also how they felt about themselves. People often referred to their body like an object that was separate to them. This idea I have called ‘this body and me’.

‘It’s all me’
At other times people spoke of how they still felt the same in themselves even though their body was different. They described their body and their sense of ‘me’ as one. At these times people described feeling free and in control. This idea I have called ‘it’s all me’.

A changing experience
These opposite experiences changed frequently for people. There were a few things which swayed how people felt about themselves and their body. This included knowledge of the stroke and its effects, the people and place around them, and the persons own attitude.

What does this mean?
There are things which help people to feel whole despite their changed body after a stroke. Knowing this may help stroke survivors, their loved ones and stroke services to have more positive experiences in the time after their stroke.

Who should I contact if I want to know more?
Emily Timothy (Physiotherapist)
Princess Margaret Hospital
Email: emily.timothy@cdhb.health.nz Phone: 03 3378938
Appendix 6

Dr F Graham
Department of Medicine (Wgnt)
Faculty of Medicine
University of Otago, Wellington

6 September 2013

Dear Dr Graham,

I am again writing to you concerning your proposal entitled “Embodiment in the transition to Life After Stroke: An exploratory study”, Ethics Committee reference number H13/060.

Thank you for your letter of 3rd September 2013 addressing the issues raised by the Committee.

The Committee are grateful for the copy of the letter from Kristina Beaufort as evidence of Peer review, acknowledging that the Rehabilitation Teaching and Research Unit approved your research proposal.

The Committee further appreciate your clarification in respect of who will be conducting the recruitment for the study noting that this will be done by the treating physiotherapist.

In respect of evaluating individual competence, the Committee are thankful for the further clarification given. The Committee note that the evaluation will be conducted by the recruiting physiotherapist who will have access to participants’ clinical records and that they will be advised to exclude people who are medically unwell, are unable to communicate in English and are unable to give informed consent.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.
Yours sincerely,

[Signature]

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Assoc. Prof. S Mann Head of Department and Associate Professor of cardiovascular medicine Department of Medi
Appendix 7

**Ngāi Tahu Research Consultation Committee**

Te Komiti Rakahau ki Kai Tahu

Tuesday, 23 July 2013.

Dr Fiona Graham,
Rehabilitation Teaching and Research Unit,
WSM&HS.

Te Aroha Dr Fiona Graham,

**Embodiment in the Transition to Life After Stroke: An Exploratory Study**

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 23 July 2013 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states “Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertakings at the University of Otago”. As such, this response is not “approval” or “mandate” for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee bases consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner: Reaching a decision that may or may not alter the original proposal."

The Committee considers the research to be of importance to Māori health.

As this study involves human participants, the Committee strongly encourage that ethnicity data be collected as part of the research project. That is the questions on self-identified ethnicity and descent, these questions are contained in the latest census.

The Committee notes the research is partly being conducted in Christchurch and the Committee suggests contacting Karen Keelan Māori Research Advisor Research Office University of Otago Christchurch.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and The Committee also requests a copy of the research findings.

The Ngāi Tahu Research Consultation Committee has membership from:

Te Rūnanga o Ōtautahi
Kāti Huiwha Rūnanga ki Puketawari
Te Rūnanga o Moeraki
This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 23 July 2013 to 9 January 2015.

Nāhaku noa, nā

Mark Brunton
Katwahakohere Rangahau Māori
Research Manager Māori
Research Division
Te Whare Wānanga o Otago
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Email: mark.brunton@otago.ac.nz
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Appendix 8

Key to transcription conventions

The transcripts for this study reflected as closely as possible the actual words and speech patterns of the interview participants. Interview extracts have been edited to illustrate points for the purposes of this paper, but all editing has occurred with the intent of retaining the original meaning of the speech.

Ellipses ( . . ) have been used to indicate where speech was omitted.

Square brackets [ ] were used to insert editorial notes or words not present on the digital recording.

Rounded brackets ( ) were used to indicate where non-verbal sounds such as laughter occurred on tape.

Underlining (yes) indicates stress or emphasis given by the person being interviewed through the use of intonation.

Italics (how) indicates interviewer speech.

Bold (it) highlights interviewer’s emphasis for purpose of data analysis.