

Spinal Cord Injury and Physical Activity: Health, Well-being and (False) Hope

by

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A Doctoral Thesis

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Abstract

It is vital that people with spinal cord injury (SCI) maintain a physically active lifestyle to promote lifelong health and well-being. Yet despite these benefits, within hospital rehabilitation and upon discharge into the community, people with SCI are largely inactive. Physiotherapists in SCI rehabilitation have been identified as the healthcare professionals (HCPs) ideally placed to promote a physically active lifestyle. However, to successfully engage people with SCI in physical activity (PA), physiotherapists have to manage their hopes and expectations of SCI rehabilitation. With all this in mind, the purpose of this thesis was to explore the role of PA for people with SCI in hospital rehabilitation and in the community. The first aim of this research was to explore the barriers, benefits and facilitators of PA for people with SCI. The second aim was to examine how hopes and expectations are managed by the physiotherapists in SCI rehabilitation and by health practitioners in a community-based leisure time physical activity (LTPA) setting. The third aim was to propose improvement to LTPA promotion for people with SCI. These aims were addressed through: 1) a meta-synthesis of the qualitative literature to identify the barriers, benefits and facilitators of LTPA for people with SCI; 2) an examination of the role of LTPA in SCI rehabilitation; and 3) an exploration of experiences of participants with SCI, and their trainers in a new type of LTPA; activity-based rehabilitation (ABR).

Framed by interpretivism, data were analysed by thematic analysis and dialogical narrative analysis. This thesis has made an original and significant contribution to the literature by revealing a deep understanding of factors that constrain and facilitate physically active lifestyles for people with SCI. For example, this research has uniquely demonstrated the role of pleasure in facilitating continued engagement in LTPA. Furthermore, this thesis identified that despite valuing the role of PA for people with SCI, active promotion of PA remains largely absent from physiotherapy practice. The dilemmas of promoting PA for the physiotherapists in SCI centres included a lack of training and education in health promotion and a concern over the false hope of recovery from LTPA opportunities such as ABR. To try and avoid false hope of recovery, the physiotherapists drew upon the therapeutic plot of acceptance and employed therapeutic actions to guide patients towards realistic hopes and expectations. An identification of three narrative types operating in ABR did reveal that some clients were exercising in the hope to walk again. However, the trainers were not preoccupied with acceptance as they also tried to avoid false hopes of ABR.

In light of these findings there are several practical recommendations for people with SCI, HCPs such as physiotherapists, the health care system and other health practitioners in community based LTPA opportunities. These practical implications are aimed at improving PA promotion and reducing the barriers to PA for people with SCI. For example, there is a need for more effective knowledge translation across the macro, meso and micro fields. At the macro level meaningful guidelines on PA for people with SCI need to be developed and embedded into UK and Ireland policies if they are to be received and utilised by physiotherapists in SCI rehabilitation and health practitioners in the community. At the meso and micro level appropriate training and education need to be delivered to physiotherapists on PA and SCI to equip them with sufficient knowledge to prescribe and promote PA. Furthermore, the knowledge on PA shared with physiotherapists needs to include the diversity of LTPA opportunities available to people with SCI including ABR. Closer communication and engagement should be implemented at the micro level between physiotherapists in SCI centres and the health practitioners working in community initiatives such as ABR to confront issues regarding hope. In addition to knowledge translation practices, there needs to be support within the healthcare system to facilitate a physically active lifestyle for people with SCI. Equally, a more critical attitude to PA promotion is called for in terms of the possible adverse consequences.

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Publications and presentations arising from this thesis

Journal Publications

- Williams, T. L., Smith, B., & Papatomas, A. (*under review*). Health promotion in spinal cord injury rehabilitation: Do physiotherapists promote physical activity?
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- Williams, T. L., Smith, B., & Papatomas, A. (2014). The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: A meta-synthesis of qualitative findings. *Health Psychology Review*, 8, 404-425.

Book Chapters

- Williams, T. L., & Smith, B. (*in press*). Disability and physical activity. In J. Piggin, L. Mansfield & M. Weed (Eds.). *Routledge handbook of physical activity, policy and practice*. London: Routledge.
- Williams, T. L., & Shaw, R. L. (*in press*). Synthesising qualitative research. In B. Smith & A.C. Sparkes (Eds.). *International handbook of qualitative methods in sport and exercise*. London: Routledge.
- Smith, B., McGannon, K. R., & Williams, T. L. (2015). Ethnographic creative non-fiction: Exploring the what's, why's and how's. In L. Purdy & G. Molner (Eds.). *Ethnographies in sport and exercise*. London: Routledge.
- Smith, B., Caddick, N., & Williams, T. L. (2015). Qualitative methods and conceptual advances in sport psychology. In S.D. Mellalieu & S. Hanton (Eds.). *Contemporary advances in sport psychology: A review*. London: Routledge.

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- Williams, T. L., Smith, B., & Papathomas, A. (2014, October). Activity-based rehabilitation from spinal cord injury: Stories of radical hope. *Association for Applied Sport Psychology (AASP) 29th Annual Conference*, Las Vegas, USA.
- Williams, T. L., Smith, B., & Papathomas, A. (2014, April). Narratives of activity-based rehabilitation for people with spinal cord injury. *5th International State-of-the-Art Congress 'Rehabilitation: Mobility, Exercise & Sports'*, Groningen, The Netherlands.
- Williams, T. L., Smith, B., & Papathomas, A. (2014, February). Narratives of activity-based rehabilitation for people with spinal cord injury. *Health and Wellbeing Research Conference*, Loughborough, UK.
- Williams, T. L., Smith, B., & Papathomas, A. (2013, December). The barriers, benefits and facilitators of leisure time physical activity among people with spinal cord injury: A meta-synthesis of qualitative findings. *British Psychological Society (BPS): Division of Sport and Exercise Psychology Conference*, Manchester, UK.

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Author Contributions

During my PhD I was successful in publishing the meta-synthesis that forms chapter three of this thesis in the journal *Health Psychology Review*. A meta-synthesis aims to systematically search, critically appraise and synthesise qualitative research pertaining to a specific research question. As the first author of this publication, I conducted the systematic search of relevant articles, quality appraisal and conceptual synthesis independently. To demonstrate reflexivity and enhance quality, I used an audit trail to document detailed descriptions of the decision making process. In line with a meta-synthesis, Prof. Brett Smith and Dr Anthony Papathomas – the second and third authors respectively – acted as a ‘critical friends’ and scrutinised the audit trail in terms of both the identification of relevant articles and process of conceptual synthesis. The second journal article to be published from this thesis was produced collaboratively with Dr Anthony Papathomas and Prof. Brett Smith. To enhance the quality and rigour, all authors contributed data from various spinal cord injury populations to produce original and significant contributions to our understanding of physical activity participation. Dr Anthony Papathomas took the lead in writing the paper and was therefore the first author. In addition to publishing journal articles, I was invited to contribute towards book chapters related to advancing the field of sport and exercise science through qualitative methods and methodology. These book chapters were not directly related to my thesis but were produced in addition to my research. That said, during the final stages of my PhD I was invited to be the lead author of book chapters that directly related to my specialist knowledge in methods of meta-synthesis and disability and physical activity arising from this thesis.

Chapter 1: Introduction

1.0 What is this PhD about?

This PhD considers the role of physical activity (PA) and spinal cord injury (SCI) from formal hospital rehabilitation through to discharge into the community. Drawing upon a range of qualitative research methods, this thesis brings together two different perspectives of PA and SCI. The first is from the medical professionals at the heart of SCI rehabilitation; the physiotherapists in the SCI centres. These physiotherapists, who specialise in neurological rehabilitation, share their views and concerns on the role of PA in SCI rehabilitation and the options for people with SCI to remain physically active in the community. The second perspective in this thesis is that of participants with SCI, and their trainers, as they share stories of their engagement in a new type of leisure time physical activity (LTPA); activity-based rehabilitation (ABR). The following chapters therefore present the perceived impact of participating in PA and the dilemmas of promoting PA for lifelong health and well-being in people with SCI.

1.1 Background

In the UK someone is paralysed by SCI every eight hours. People with SCI are faced with an immediate loss of function, reduced mobility and are at risk of future complications including secondary health conditions (Hitzig et al., 2008; Chen et al., 2011; Canning & Hicks, 2014), poor mental health and increased disability (Krause & Saunders, 2011; Gorgey, 2014). Being physically active can not only prevent secondary health conditions among people with SCI, but also has the capability to improve overall health, well-being and quality of life (Martin Ginis et al., 2012; Tomasone et al., 2013). As a result, PA has been championed as an important component of rehabilitation and a necessity for lifelong health and well-being (Martin Ginis et al., 2012). Despite the benefits of PA, people with SCI are within the most inactive segment of society that comprises disabled people (Martin Ginis, 2010a; Letts et al., 2011). Therefore, health promotion through PA is a significant and timely issue for the spinal cord injured community (Tomasone et al., 2014). Important in this process of promotion are the people (i.e. who) that are deemed credible to convey PA messages and the contexts (i.e. where) in which this might effectively occur.

This thesis focuses upon two contexts in which people with SCI are physically active to broadly explore PA promotion and the barriers, benefits and facilitators of LTPA. The first context is formal hospital rehabilitation in national SCI centres. Following SCI, the person undergoes a lengthy period of specialist in-patient rehabilitation within a SCI centre. A vital

purpose of rehabilitation is to teach people how to take care of a changed body and live independently with SCI to achieve optimum health and well-being (Mulligan et al., 2011). A recent focus on healthcare promotion for this population has identified healthcare professionals (HCPs) as credible messengers for conveying PA messages to people with SCI (Letts et al., 2011; Smith, 2013; Smith et al., 2015). HCPs in rehabilitation are perceived by spinal cord injured patients to be valued, trusted and reliable sources of information. Furthermore, rehabilitation in SCI centres has been identified as a key context of the start of lifelong health and well-being through PA promotion (Letts et al., 2011; Smith et al., 2015). Some consider that the HCPs best placed to promote a physically active lifestyle to people with SCI are physiotherapists (Morris & Williams, 2009; O'Donoghue & Dean, 2010; Walkeden & Walker, 2015). This is because “the roles of physiotherapists as promoters, preventers and rehabilitators puts them in an ideal position to influence exercise behaviours in every individual they treat” (McGrane et al., 2015, p.11). Moreover a key responsibility of physiotherapists in the context of rehabilitation is to provide “support for people with disabling conditions to attain independence and self-determination to be physically active for their long term health” (Mulligan et al., 2011). Currently however, little is known about the PA and health promotion practices within physiotherapy (McGrane et al., 2015; Walkeden & Walker, 2015) and specifically for SCI rehabilitation.

The second context explored in this thesis is a community based LTPA initiative called activity-based rehabilitation (ABR). In an effort to help reverse inactivity following SCI, the first ABR centre – Neurokinex – was recently opened within the UK. In ABR centres, people with SCI can pay to exercise with the aid of a specialist health practitioner within an adapted gym facility. ABR is characterised by intensive exercise programmes which aim to maximise an individual’s physiological, functional and neurological potential (Jones et al., 2014). At the same time, through regular exercise, ABR is marketed to improve health and well-being and improve quality of life for people with SCI (Neurokinex, 2014). Presently, there is a lack of understanding concerning the premise of ABR. Neurokinex offers the opportunity to identify how barriers to LTPA were overcome, what factors facilitate a physically activity lifestyle in the community, and the impact of ABR on the lives of spinal cord injured people. Accordingly, by examining the PA promotional practices in SCI rehabilitation centres and understanding what works in relation to facilitating PA in the community, governing bodies, disability sport and exercise organisations and rehabilitation centres will be in a better position to support disabled people to be physically active for life.

This thesis therefore explores both the PA promotional practices of physiotherapists in SCI rehabilitation and the experiences of ABR from people with SCI and their trainers.

1.2 Overview of the thesis

This thesis unfolds as follows: **chapter two** begins with a review of the current literature pertaining to the research context. This broadly includes an overview of the theoretical and conceptual ideas related to disability, health, well-being, SCI rehabilitation and narrative. **Chapter three** is the first empirical results chapter comprising a systematic review and qualitative meta-synthesis of the barriers, benefits and facilitators to LTPA among people with SCI. The meta-synthesis is a rigorous and explicit research method that was drawn upon to enrich the understanding of the factors that constrain and promote LTPA in the SCI population. This provides a contextual background to the project and offers a rationale to further explore LTPA participation for this population. **Chapter four** introduces the paradigmatic and methodological underpinnings of the research, together with the methods used to collect and analyse the data. It further explains the choice of tale to represent the findings, the ethical considerations encountered and possible criteria of which this thesis may be judged against for research quality. **Chapter 5** then provides the contextual background to Neurokinex by offering a brief historical overview of the organisation and current understandings of ABR.

The main body of empirical findings that constitute this thesis are chapters six through to nine. **Chapter six** addresses the *beliefs and values of physiotherapists* in SCI rehabilitation concerning PA for this population. The focus of this chapter concerns the *role* of physiotherapists in *promoting PA* both within rehabilitation and on discharge from this context into the community. Furthermore this chapter considers the physiotherapists' perceptions of ABR and introduces the perceived *false hope* offered by this type of LTPA. **Chapter seven** builds upon this latter issue and concentrates on the *process* of managing hope and expectation within SCI rehabilitation undertaken by the physiotherapists. **Chapters eight** and **nine** turn attention to experiences of ABR by people with SCI. Firstly, these chapters relate to the meta-synthesis presented in chapter three by identifying how participants overcame barriers to LTPA, the perceived benefits of participation and what facilitated continued engagement in the programme. Specifically, chapter eight considers the *content* of the participants' stories and addresses what the physical and narrative environment of Neurokinex offers the participants in this context. Conversely, chapter nine examines the

narrative structure and form of participants' stories. This chapter identifies the *types of narrative* that participants draw upon and how these stories influence their hopes of ABR. Secondly, these chapters attend to concerns raised by the physiotherapists in chapters six and seven by addressing the PA messages promoted at Neurokinex and how hopes and expectations of ABR are managed in this context.

To conclude, **chapter ten** draws the thesis to a close by drawing conclusions across all of the empirical research and summarises its contribution to knowledge. This chapter includes the empirical and methodological implications of this research. Furthermore, practical considerations regarding SCI and LTPA are highlighted both within the context of rehabilitation, and in community-based organisations.

Chapter 2: Review of the Literature

2.0 Overview

This PhD thesis draws upon a range of theoretical and conceptual ideas related to disability, health, well-being, rehabilitation, physical activity (PA) and narrative. In this chapter the literature is reviewed pertaining to these topics as each underpins this research project. The first section addresses the models by which disability can be understood and the consequences of defining disability in this way. The second section focuses attention on health and well-being and introduces the role of rehabilitation and PA in promoting health and well-being following spinal cord injury (SCI). The final section establishes narrative as a method of inquiry to explore individuals' experiences of illness and injury and understand what motivates spinal cord injured people to be physically active. Overall this chapter provides a rationale for the research project and concludes by outlining the subsequent aims and research questions.

2.1 What is disability?

This PhD explores how disabled people – those with acquired SCI – experience a type of PA referred to as activity-based rehabilitation (ABR). Moreover it explores hopes and expectations following SCI, and how healthcare professionals (HCPs) (e.g. physiotherapists in SCI rehabilitation) and health practitioners (e.g. trainers at Neurokinex) attempt to manage these hopes and expectations. Therefore in the first instance, it is imperative to critically examine how disability is explained and understood. As Smith and Bundon (*in press*) describe, having a grasp on how disability is explained and understood is vital for individuals working with disabled people in any context. This is because the definition of disability is fundamental in shaping medical practices to improve health, rehabilitation programmes and how research with disabled people is carried out (McDermott & Turk, 2011). Yet there are a variety of models and theories which aim to define disability with often contrasting perspectives and profoundly different implications for the lives of disabled people. The focus of this first section will be upon the two key models of disability – the medical model and social model¹ – before turning attention to more conceptual models. These conceptual models include the International Classification of Functioning, Disability and Health, the social relational model, the interactional model and the human rights model of disability.

¹ The social model is not considered to be a social theory (Thomas, 2008), or a model in its own right, because it lacks the necessary components to satisfy these definitions (Owens, 2015). It may actually be closer to a concept (Smith & Bundon, *in press*), but is referred to as a 'model' throughout this thesis to reflect the literature.

2.1.1 The medical model

The medical model, sometimes referred to as the individual model of disability, was historically the dominant model for understanding disability. Through this model, disability was defined as the inability to perform a task considered *normal* for any person due to impairment (Thomas, 2007; Smith & Bundon, *in press*). Therefore in the medical model, disability is described as “caused” by parts of the body that do not work “properly” (Smith & Perrier, 2014). The medical profession – in a powerful position to both diagnose and cure illness – created and perpetuated discourses that shaped disability as merely a biological product (Brittain, 2004). Despite this dominant medical discourse historically shaping how people understood disability, the medical model has been profoundly criticised. One problem with the medical model is that by defining disability based on biological assumptions of normality, the role of wider social-cultural, physical and political forces that construct ‘normal’ are overlooked and unchallenged (Brittain, 2004; Meekosha & Shuttleworth, 2009). Furthermore, as Smith and Perrier (2014) point out, this can create a dangerous ‘normal/abnormal’ dualism:

Defining disability as any lack of ability resulting from an impairment to perform an activity within the range considered normal, the medical model constructs disabled people as defective (i.e. ‘not normal’) and others (‘the normals’) as definitive or superior human beings who can assume authority and exercise power (p.4).

Within the context of rehabilitation, the medical model asserts that the focus of treatment by HCPs is to reduce impairment. This emphasis on the need to reduce impairment further reinforces the negative idea that an individual seeking rehabilitation is ‘abnormal’ (Kielhofner, 2005; Roush & Sharby, 2011). The danger with this view is that “when rehabilitation carries the latent message that impairment is not a good thing, those who received rehabilitation but are not able to eliminate their impairments are likely to internalise a negative image of themselves” (Kielhofner, 2005, p.490).

Another criticism of the medical model is that it depicts disability as a personal physical tragedy or a psychological trauma that should be *overcome* (Brittain, 2004; Smith & Bundon, *in press*). The aim of the medical profession is therefore to eliminate disease or impairment to restore function (Lutz & Bowers, 2005; Roush & Sharby, 2011; Morris et al., 2014). If disease or impairment cannot be ‘cured’ then medicine turns its attention to rehabilitation services in an effort to maximise physical and psychological function and/or

“facilitate the prosthetic disguise of impairment” (Thomas, 2007, p.61). This assumption that “impairment is ‘objectively’ a negative state provides the rationale for rehabilitation’s operating principle that reducing or eliminating impairment is unquestionably good” (Kielhofner, 2005, p.488).

A further criticism of the medical model is that it locates the ‘problem’ of disability within the individual (Goodley, 2013; Smith & Bundon, *in press*). By locating the cause of disabled people’s problems squarely within them and their impairments, disabled people become responsible for their own health (Brittain, 2004; Smith & Perrier, 2014). In this light, disabled people are seen as a burden on society when they cannot take care of themselves and request help and assistance (Brittain, 2004). Reducing disability through rehabilitation therefore additionally serves to lessen the social burden of disabled people (Keilhofner, 2005). This emphasis on rehabilitation has led to the growth of professionals in the field of disability and inevitably reinforced the perception that disabled people are dependent upon others (Thomas, 2007). Accordingly, the medical model and its preoccupation with impairment refuse to acknowledge any societal factors that contribute to the experience of disability. The results of these criticisms saw the development of a new model that shone light on the social and cultural meaning of disability over the medical and biological perspective.

2.1.2 Social model

Understanding disability through a social model situates disability as a consequence and problem of society. The UK social model of disability² was advocated by Michael Oliver in the 1980’s and was at the heart of the disabled people’s movement in the UK (Thomas, 2007). This model rejects the causal link between impairment and disability and instead asserts that disability results from the social restrictions (or barriers) imposed upon people with impairment. Thus, the social model “views disabled people as socially oppressed and it follows that improvements in their lives necessitates the sweeping away of disablist social barriers and the development of social policies and practices that facilitate full social inclusion and citizenship” (Thomas, 2007, p.15). A key strength of the social model was its impressive political power as it influenced anti-discrimination legislation through Disability Discrimination Acts (Lutz & Bowers, 2005; Shakespeare, 2014). Consequently, disabled

² It is worth noting there are different forms of the social model. For example, there is the Nordic social relative model of disability, and the North American social model that differ from the UK model (Smith & Bundon, *in press*). The focus here is on the UK social model that was derived from the Union of Physically Impaired Against Segregation (UPIAS) and underpinned by Marxism (Shakespeare, 2014).

people, by law, should have equal access and total inclusion within society. The social model was revolutionary not only for highlighting social exclusion, it also liberated disabled people from the being 'the problem'. As Smith and Perrier (2014) assert:

Rather than themselves being the 'problem' and the 'solution' traced to their own individual body, disabled people have been enabled by the social model to recognise that society is often the problem and that solutions are to be found there, 'outside' their own bodies (p.10).

Whilst many important achievements have been accomplished under the social model of disability, this model has also faced intense criticism. As Shakespeare (2014) contends, the "strength and simplicity of the strong social model of disability has created as many problems as it has solved" (p.14). For example, the simplicity of the social model has been critiqued for creating a dualism by conceptually separating impairment from disability (Thomas, 2007). Due to social models of disability setting aside impairment, the body is ultimately excluded from understandings of disability. For Hughes and Paterson (1997), this exclusion is problematic: "disability is experienced in, on and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning" (p.335). The reason for this exclusion was simple, including impairment or 'the body' would have conceded to the biological reductionism of the medical model (Thomas, 2007).

Another criticism of the social model is that its focus on social arrangements has ignored people's lived experience of disability (Shakespeare, 2014). The lives of disabled people are influenced by both the fundamental aspects of impairment and their social context (Lutz & Bowers, 2005). Furthermore, if disability is solely concerned with social barriers and not individual experience, then society does not need to cater for the individual needs and services of disabled people (Shakespeare, 2014). A further problem with the focus on barrier removal is that a barrier free world is constrained by the natural environment and it is not practically possible to change the social environment to positively impact all disabled people (Shakespeare, 2014). As Brittain (2004) insists, "such transformations alone will do little or nothing to destroy the underlying *disablist* values within society or the institutional structures within which people with disabilities are forced to operate" (p.431, emphasis in original). The social model also situates HCPs in rehabilitation in a precarious position. If disability is concerned with social barriers and not impairment, then "attempts to mitigate or cure medical

problems may be regarded with intense suspicion. They will appear to be irrelevant or misguided responses to the true problem of disability” (Shakespeare, 2014, p.18). Accordingly, neither the medical model nor social model reflects the multifaceted nature of disability (Lutz & Bowers, 2005). What this called for, was the development of a conceptual model of disability that captured both the physical and social experiences of disabled people.

2.1.3 Conceptual models

The above critiques of both the medical model and social model of disability have led to the development of many conceptual models of disability. These include, but are not limited to, the International Classification of Functioning, Disability and Health, the social relational model, the interactional model and the human rights model of disability. The World Health Organisation (WHO) assigned a task force to develop a conceptual approach to disability that incorporated both the medical model and social model. What they produced is now the most dominant form of classifying disability: The International Classification of Functioning, Disability and Health (ICF) (Lutz & Bowers, 2005). The ICF is a framework for measuring both health and disability (see Figure 2.1). Accordingly, the WHO adapted their understanding of disability as an umbrella term which covers impairments, activity limitations and participation restrictions. Therefore “disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives” (WHO, 2015a).

The biopsychosocial model, at the heart of the ICF is a functional model that offers a practical way to understand the multifaceted nature of disability (Shakespeare, 2014). The ICF does attempt to integrate medical and social meanings of disability, and can provide a rich description of an individual based on their classification (Thomas, 2007). However, the ICF does have limitations. As McDermott and Turk (2011) highlight “the medical and health components are well described, but the definitions of participation and environment, key elements promoted by the model, are poorly identified and difficult to quantify” (p.2). Moreover, with a focus on impairment, the ICF continues to place the disabling condition rather than the individual’s experience of disability at the heart of research and interventions (Lutz & Bowers, 2005).

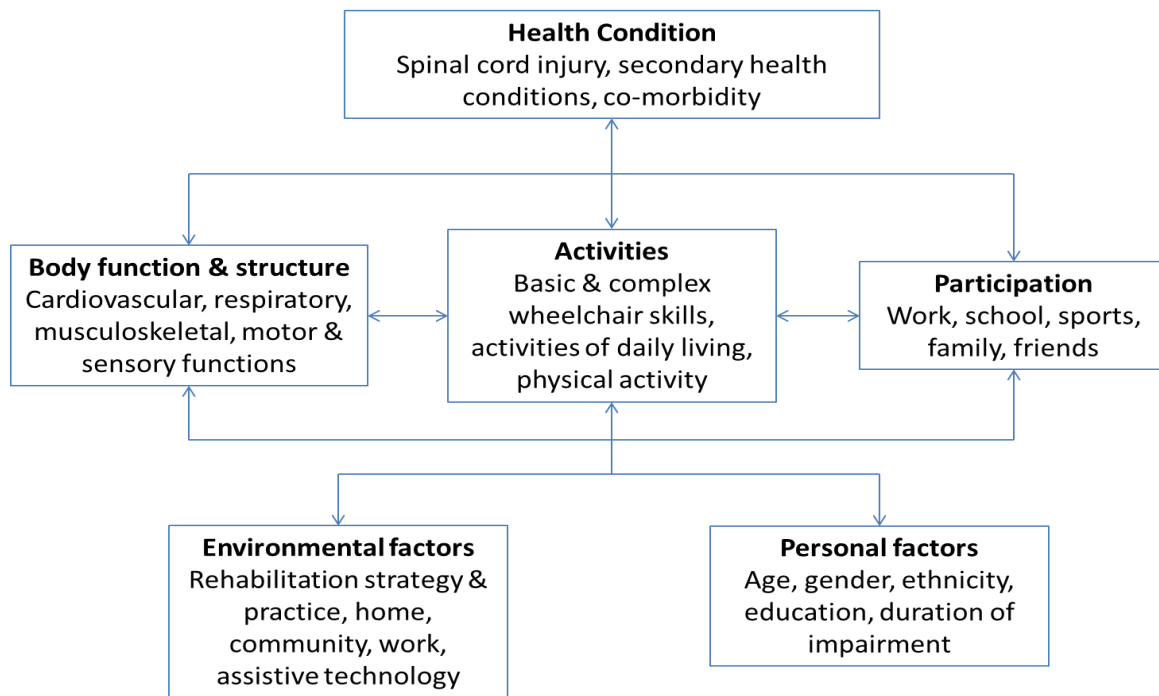


Figure 2.1: An example of the ICF in SCI research (adapted from de Groot et al., 2009)

Two further models that aimed to encompass the complexity of disability were developed by disability scholars. These were the *social relational model* (Thomas, 2007) and the *interactional model* (Shakespeare, 2014). The social relational model proposed by Thomas (2007) builds upon the social model and argues for theories that “engage both with social structure (order) and social agency (action) and should therefore accommodate analyses of social relations and social forces that construct, produce, institutionalise, enact and perform disability and disablism” (p.181). Accordingly, the social relational model positions disability as a social relationship between people and conceptualises disablism as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the social engendered undermining of their psycho-emotional well-being” (Thomas, 2007, p.73). Importantly, this model encompasses and extends disablism by recognising that people can experience many forms of social oppression (i.e. structural disablism and psycho-emotional disablism) that emerge not from within the individual but from relationships with structures and people (Smith & Bundon, *in press*). Thus, while structural barriers can restrict the activities of people with impairments, society can hurt them on a personal level through insensitive comments and behaviours. As Thomas (2007) explains: “social barriers ‘out there’ certainly place limits on what people *can do*, but psycho-social disablism places limits on who they *can be* by shaping individuals’ ‘inner worlds’, sense of ‘self’ and social behaviours” (p.72, emphasis in original).

One issue with the social relational model is that with social oppression operating at its heart, disability research is committed to finding all disabled oppressed (Shakespeare, 2014). With this in mind, Shakespeare (2014) proposed an interactional model of disability that aims to “neither reduce disability to an individual medical problem, nor neglects the predicament of bodily limitation and difference” (p.2). This interactional approach suggests there are many different factors at play that could be addressed to improve quality of life of people with impairments. For example: “coaching or therapy to improve self-esteem; medical intervention to restore functioning or reduce pain; aids and adaptations; barrier removal; anti-discrimination and attitudinal change; better benefits and services (Shakespeare, 2014, p.83).

Conversely, Shakespeare (2014) critiques the social relational model for aligning too closely with the social model, and Thomas (2007, 2008) problematises the interactional model for favouring a biological reductionist view of disability and therefore supporting the medical model. Accordingly, while both models have their limitations, they each seek to contend that disabled people live lives shaped by impairment and the effects of disablist social factors (Thomas, 2008). The combined perspectives of both the medical and social models of disability do however leave HCPs in rehabilitation, especially physiotherapists, in somewhat of a paradoxical position. As Roush and Sharby (2011) ask, “how do we practice in the medical model and intervene to minimise the effects of a disability while recognising and celebrating disability as diversity?” (p.1718). To leave the medical model behind and adopt a more conceptual approach to disability, Roush and Sharby (2011) suggest that physiotherapists should be educated to gain a better understanding of the complexity of disability beyond physical limitation.

Another model which HCPs could draw upon to address disablist issues for their patients is the human rights model of disability. This model is grounded in the United Nations Convention of the Rights of Persons with Disabilities (United Nations, 2006). The Convention recognises that disabled people have the right to access services in all areas of citizenship including health, rehabilitation and PA (see example articles in Appendix A). In contrast to other models, the Convention is underpinned by eight general principles which capture how it understands disability. These are: 1) respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; 2) non-discrimination; 3) full and effective participation and inclusion in society; 4) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; 5) equality of opportunity; 6) accessibility; 7) equality between men and women;

and 8) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (United Nations, 2006).

2.2 Health and well-being following spinal cord injury

SCI is a serious neurological condition most commonly caused by a traumatic force that damages the spinal cord. This damage to the spinal cord can result in a loss of function in one or more limbs depending upon the location and severity of the injury. The degree of impairment depends upon the level of paralysis and whether the spinal cord is partially ruptured (incomplete injury) or completely severed (complete injury) (NHS, 2014). As Figure 2.2 shows, complete injury to the cervical vertebrae (neck bones) results in paralysis of all four limbs which is referred to as quadriplegia. A complete injury to the thoracic vertebrae, and below, results in paraplegia whereby there is paralysis in the legs accompanied by full use of arms and hands. An incomplete injury is where only part of the spinal cord is damaged meaning individuals will experience only impaired function and in some cases can escape paralysis. Trauma that results in broken or fractured vertebrae of the spinal column will not lead to paralysis if there is no damage to the spinal cord and full recovery is possible (NHS, 2014).

Spinal cord injured individuals are faced with immediate loss of function and reduced mobility and are at risk of serious future complications to their health and well-being (Chen et al., 2011; Hitzig, et al., 2008; Krause & Saunders, 2011). Moreover, following SCI people may experience frustration at loss of independence and freedom, despair over lack of control over one's life and body, increased dependence on spouse and others for personal care, disrupted relationships and difficulty coming to terms with the injury (Dijkers, 1996; Pentland et al., 2002; DeSanto-Madeya, 2006; Chun & Lee, 2008; Craig, et al., 2009; Soundy et al., 2013). As Cross et al. (2006) describe, "For some, SCI is experienced primarily as a 'broken body'. Partial or complete paralysis of two or four limbs is the dominant feature of SCI. For many however, spinal cord injury goes beyond the body and represents a 'broken person'." (p.183). Overall the sudden and significant changes brought about by SCI present an individual with numerous challenges to both health and well-being. This next section explores health and well-being following SCI, and considers the role of rehabilitation and PA.

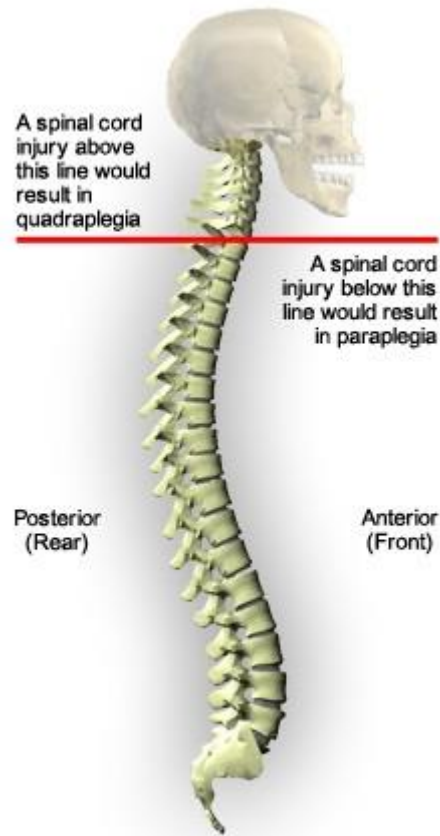


Figure 2.2: SCI and level of paralysis (taken from: www.apparelyzed.com)

2.2.1 Health

Damage to the spinal cord, and subsequent paralysis, pose a serious risk to an individual's health. The WHO defines good health as a "state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity" (WHO, 2015b). This definition has remained unchanged since 1948 and was originally celebrated for overcoming health as simply the absence of disease by including physical, mental and social domains (Huber et al., 2011). However, there is now a growing body of literature that criticises this definition for the inclusion of the word *complete* in relation to physical well-being (Bok, 2008; Godlee, 2011). As Smith (2009) states, the problem with the requirement for complete health would leave *most* of us unhealthy *most* of the time. Furthermore this definition contributes to the medicalisation of society and sits more comfortably within the medical model of disability. Another criticism with this definition is that it labels the growing population of people living with chronic diseases and disabilities, including those with SCI, conclusively ill (Huber et al., 2011). According to Huber et al., (2011), this definition "minimises the role of the human capacity to cope autonomously with life's ever changing physical, emotional, and social challenges and to function with fulfilment and a feeling of

wellbeing with a chronic disease or disability” (p.343). A more dynamic understanding of health can be conceptualised as “the ability to adapt and self-manage” in the three domains of health: physical (physiological); mental (psychological); and social (relationships with others) (Huber et al., 2011, p.343).

Accordingly, disabled people define their health differently from the WHO definition. As Nazli (2012) explains, “For people with disabilities, health does not mean being disabled; rather, it means not being ill. Thus, unhealthiness equals illness. Although these people have physical disabilities, they are healthy because they are not ill” (p.238). Therefore, disabled people can perceive themselves to be healthy despite their impairment. While it is understood that people with SCI can achieve and maintain good health, this is not a straightforward task. In terms of physical health, the damage to the spinal cord results in many changes to both the motor and sensory systems which create difficulties for the individual trying to deal with their injury. For example, spinal cord injured individuals may experience a loss of mobility or in the worst case scenario, complete paralysis (Gensel, 2014). There are a plethora of secondary health conditions associated with SCI including pressure ulcers, urinary tract infections, chronic pain, obesity, respiratory dysfunction and cardiovascular disorders (Hitzig, et al., 2008; Chen et al., 2011; Canning & Hicks, 2014). Additionally these secondary health conditions can present as risk factors for poor mental health, increased disability and a decrease in quality of life and life expectancy (Krause & Saunders, 2011; Canning & Hicks, 2014). In terms of mental/psychological and social health, these have been more broadly recognised in the literature as constructs of well-being.

2.2.2 Well-being

The concept of well-being generally refers to “optimal psychological function and experience” (Ryan & Deci, 2001, p.142). There are however a variety of terms and definitions of well-being currently used in the literature. This variation is due to the debate over what constitutes optimal function and experience, and ultimately what is the “good life” (Ryan & Deci, 2001). In recent years, research has highlighted two distinct perspectives of well-being originating from two different philosophical traditions. The first of these is the hedonic perspective and is founded upon the belief that the goal of human life is to pursue happiness and pleasure (Keyes et al., 2002). The hedonic view of well-being in psychology comprises a subjective evaluation of one’s quality of life and happiness, consequently labelled subjective well-being (SWB). SWB therefore consists of three elements; life

satisfaction, increased positive affect and an absence of negative affect (Diener, 2000; Ryan & Deci, 2001; Keyes et al., 2002).

The second view is the eudaimonic perspective, which in contrast to SWB proposes that “well-being consists of more than just happiness. It lies in the actualization of human potentials” (Ryan & Deci, 2001, p.143). In other words, eudaimonic well-being focuses on psychological growth and development of an individual, rather than obtaining happiness, as essential to human development (Keyes et al., 2002). This view has been labelled psychological well-being (PWB) and is concerned with six key dimensions that indicate human flourishing and the actualisation of one’s true potential: self-acceptance, positive relatedness, autonomy, personal growth, life purpose and environmental mastery (Ryff & Keyes, 1995). These six dimensions however mainly consist of personal indicators of PWB. Therefore further aspects of social well-being were proposed to indicate social flourishing and are represented by a positive attitude towards society, a valued contribution towards society and social belonging (Keyes, 1998; Lundqvist, 2011).

Whilst hedonism and eudaimonism are two distinct constructs of well-being, there are some mutually influential components (Keyes et al., 2002; Linley et al., 2009). For example, without happiness and life satisfaction it is unlikely that psychological growth and development will occur, and when meaningful life experiences are lacking, happiness and life satisfaction may decrease (Lundqvist, 2011). To gain a comprehensive overview of well-being it is therefore important to explore both the hedonic and eudaimonic perspectives (Lundqvist, 2011). However research into well-being can often use SWB and PWB interchangeably with constructs of one perspective being misunderstood for the other. This leads to a clouded understanding of what the term well-being is actually referring to (Jovanovic, 2011). The confusion in well-being terminology has been seen in both health (Durkin & Joseph, 2009) and sport psychology literature (Lundqvist, 2011). As well as SWB and PWB, terms such as psychosocial, mental, and emotional well-being are utilised without the underpinning knowledge of their theoretical and philosophical position. Without clearly defining well-being to either the hedonic or eudemonic perspective, the translation of the research into evidence based practice can be problematic. As Lundqvist (2011) warns:

With vague or diverse definitions and indicators...study results will be difficult to interpret within a larger theoretical framework, general conclusions from the extant literature will be difficult to draw, and the literature will be characterized by

confusion regarding what construct is actually studied. In the worst case, misleading conclusions might hamper both the progress in this field of research and the application of evidence-based interventions (p118-119).

Despite the confusion over the terminology, becoming disabled following SCI has been shown to profoundly impact well-being. As De-Santo-Madeya (2006) contends, the “psychological impact of paralysis is more devastating than the inability to walk” (p.276). Certainly, the adaptation process after SCI is extremely complex and involves all components of health (physical health) and well-being (SWB & PWB) (Suarez et al., 2013). In terms of SWB, SCI can lead to elevated levels of depression and anxiety, and decreased self-esteem (Krause & Saunders, 2011; Geyh et al., 2012; Post & van Leeuwen, 2012). Notably, depression has been reported as the most common psychological trauma following SCI. A recent meta-analysis of 1053 studies identified the mean prevalence estimate of depression diagnosis after SCI to be 22.2% (ranging from 18.7% to 26.3%) (Williams & Murray, 2015). In association with depressive symptoms, people with SCI have higher comparative risks of feelings of helplessness, poor quality of life and decreased life satisfaction (Craig et al., 2009). Moreover, suicide rates among spinal cord injured people are three times higher than the general population (Cao et al., 2014). Furthermore, in terms of PWB, including social well-being, those with SCI report a loss of purpose in life and increased social isolation and exclusion (Geyh et al., 2012).

In spite of the negative consequences of trauma, people with SCI can experience positive changes resulting from the struggle and psychological consequences following SCI (Pollard & Kennedy, 2007). These positive experiences following trauma such as SCI are illustrative of post-traumatic growth (Pollard & Kennedy, 2007; Day, 2013) and therefore improved PWB. Post-traumatic growth is defined as the phenomenon of “positive change following the experience of trauma and adversity” (Hefferon et al., 2008, p.32). Experiences that indicate post-traumatic growth include strengthened relationships with others, valued changes in personal goals, a greater appreciation of life, a deeper understanding of the world and the recognition of new possibilities (Chun & Lee, 2008; Chun & Lee, 2010). Thus, a vital role of rehabilitation is to assist people to adapt and self-manage their health and well-being (SWB & PWB) following the traumatic onset of SCI. This role is explored further in the next section.

2.2.3 Rehabilitation to life-long physical activity

Formal rehabilitation in an SCI centre is the first step towards restoring health and well-being of a patient with acquired SCI. The role of rehabilitation goes beyond promoting functional independence. In line with the biopsychosocial model of the ICF, rehabilitation aims to restore “the individual to the highest level of participation, and returning individuals to the life they want as far as their disability will allow” (Nunnerley et al., 2013, pp.1164-1165). Thus, a vital purpose of rehabilitation is to educate people how to take care of a dramatically altered body and teach people to live independently to achieve optimum health and well-being (Mulligan et al., 2011). Physiotherapy, or physical therapy, draws upon PA to address the problems that are associated with SCI such as muscle weakness and poor posture, as well as teaching patients activities of daily living, such as how to transfer from the floor to their wheelchair (Mulligan et al., 2011; WCPT, 2012). These skills are essential for people to master if they are going to be able to live independently upon discharge from the SCI centre into the community (Nunnerley et al., 2013).

To continue to improve and maintain health and well-being upon discharge to the community, and avoid the onset of secondary health conditions, it is vital that people remain physically active (Hitzig et al., 2008; Chen et al., 2011; Canning & Hicks, 2014). This is because PA has been identified as a means to alleviate or prevent many of the health and well-being complications associated with SCI. For example, PA has been shown to reduce levels of perceived musculoskeletal and neuropathic pain (Norrbrink, et al., 2012), decrease the risk factors of cardiovascular disease and type 2 diabetes (Buchholz et al., 2009), and lead to greater functional capacity such as ease of transfer thereby improving quality of life (Martin Ginis et al., 2012). Furthermore, PA can impact SWB through reducing depression and enhancing physical self-concept (Hicks et al., 2003), and improve PWB through facilitating experiences (such as personal control, responsibility and risk taking) that promote post-traumatic growth (Day, 2013). Despite the array of health and well-being benefits to be gained from regular PA, most people with SCI live insufficiently active lifestyles. An estimated 50% are completely sedentary (Martin Ginis et al., 2010a). The human cost of physical inactivity for people with SCI is vast as individuals unnecessarily endure acute and chronic health problems preventable through exercise (Gorgey, 2014). Therefore, health promotion through PA, including the factors that promote and constrain a physically active lifestyle, is a significant and timely issue for the spinal cord injured community (Tomasone et al., 2014).

Formal rehabilitation in SCI centres had been identified as a key context for promoting a physically active lifestyle for lifelong health and well-being (Letts et al., 2011; Smith et al., 2015). Within rehabilitation and the community, physiotherapists have been identified as the HCP best placed to convey PA messages (Morris & Williams, 2009; O'Donoghue & Dean, 2010; Smith et al., 2015; Walkeden & Walker, 2015). For example, their role as “promoters, preventers and rehabilitators puts them in an ideal position to influence exercise behaviours in every individual they treat” (McGrane et al., 2015, p.11). Moreover, physiotherapists in rehabilitation have a responsibility to provide “support for people with disabling conditions to attain independence and self-determination to be physically active for their long term health” (Mulligan et al., 2011, p.408). In addition, people with SCI trust and value physiotherapists as credible messengers of PA information (Letts et al., 2011; Smith et al., 2015).

To successfully engage people with SCI in PA, physiotherapists have to manage their hopes and expectations. On the one hand, patients need hope for the future if they are to engage in rehabilitation and learn the required skills to manage their SCI (Soundy et al., 2010; Harvey et al., 2012). On the other hand, physiotherapists need to ensure they foster hopefulness without promoting false hopes of recovery following SCI (Soundy et al., 2014). Therefore the physiotherapists are in a delicate position of balancing what is hoped for, while not crushing a patient's hope altogether. Thus, managing hopes and expectations of SCI rehabilitation is essential if people are to remain physically active for their health and well-being once their functional recovery has reached a plateau (Harvey et al., 2012; Soundy et al., 2013; van Lit & Kayes, 2014). Regardless of the perceived importance of physiotherapists in promoting PA, there is a gap in the literature identifying what physiotherapists think about PA for people with SCI, what they do in relation to promoting PA and how they manage hope and expectation. This is addressed in this thesis.

2.3 Narrative

Narrative is a form of inquiry that has been extensively used to interpret the embodied lived experience of illness and injury. Faced with chronic illness or disabling injury, narrative is one cultural form by which people formulate and express their experience of illness and suffering (Hydén, 1997; Frank, 2013). This is because narratives are essential means by which people make sense of their lives and embodied experiences. As Frank (2013) explains, serious illness and injury represents a loss in the “destination and map” that have previously

guided an individual's life (p.1). These experiences bring disruption and confusion into people's lives. Accordingly, telling stories is a way that people make sense of experience (Charmaz, 1999; Crossley, 2000), produce and maintain a sense of identity (Ricoeur, 1988; Bury, 2001) and reconstruct a sense of order in lives disrupted by serious illness and injury (Frank, 2010; Frank, 2013).

Before exploring the role of narrative in shaping personal interpretations of disability, illness and injury, it is first important to expand upon what is narrative. Humans have been widely accepted as storytellers, and therefore this forms an underlying assumption that humans lead *storied lives* (Crossley, 2000; Partington et al., 2005; Phoenix & Sparkes, 2006; Smith, 2010). Thus, people express themselves through stories and make sense of their lives and experiences by telling stories. Telling stories not only offers a space to connect with others, but the opportunity to reflect back upon one's life (Horricks et al., 2002; Medved & Brockmeier, 2008). Furthermore, people transmit *meaning* by telling stories, and understanding meaningful experience is a central component of narrative inquiry. As Garro and Mattingly (2002) explain, "Narrative is a fundamental human way of giving meaning to experience. In both telling and interpreting experiences; narrative mediates between an inner world of thought – feeling and an outer world of observable actions and states of affairs" (p.1). Similarly, Mayer (2014) suggests "Stories imbue our experience with "meaning." Events become meaningful to the extent that they can be fit into or evoke some larger narrative about ourselves or our world... It is impossible to say who we are without telling a story" (p.7).

People tell stories about their lives that convey, express, and formulate *personal* thoughts and feelings in relation to particular experiences. Whilst these experiences are personal to the individual, the stories people tell are socially constructed (Frank, 2013). As Phoenix and Sparkes (2006) illuminate:

People resort to a mode of telling with which they feel familiar. In this sense, narrative is a form of social practice in which individuals draw from a cultural repertoire of stories that they then assemble into personal stories... It is through this social aspect of narrative that the dominant narratives available in culture may act to shape not only who we think we are, but also who we think we can become in the future (p.109).

The dominant narratives available in culture therefore act as a resource, or template, by which people can draw upon to tell their own stories (Frank, 2010). Thus, a useful distinction between narrative and story can be made. Broadly speaking, narrative can be understood as “a complex genre that routinely contains a *point* and *characters* along with a *plot* connecting *events* that unfold *sequentially* over *time* and in *space* to provide an overarching *explanation* or *consequence*” (Smith & Sparkes, 2009, p.2, emphasis in original). Stories on the other hand, are individual tales, or specific acts of telling, constructed from narratives that social relations, culture and society make available to us (Smith, *in press*). This is not to suggest that people do not have agency in telling their stories. Rather, people adapt established and recognisable narrative resources to tell individual stories (Smith & Sparkes, 2009; Frank, 2013). However, for some narrative scholars, there is no distinction between narrative and story (e.g. Riessman, 2008). Indeed, as Frank (2013) confesses, “since narratives only exist in particular stories, and all stories are narratives, the distinction is hard to sustain” (p.224). Nevertheless, a distinction between narrative and story is valuable to “recognise the uniqueness of each individual story, while at the same time understanding how individuals do not make up stories by themselves” (Frank, 2010, p.119).

In addition, narratives are not only resources for telling personal stories; they are also actors as they *do* things on, in, for and with us (Frank, 2010). In other words, narratives are crucial actors in helping *create* and *shape* experience through the ordering of events. Stories have the capacity to *act* in a way that guides and informs our actions and future possibilities (Frank, 2006). For example, stories work *for* people by providing a map or destination to follow, and *on* people by teaching what to pay attention to and how to respond to certain actions. As Frank (2010) describes, “People do not simply listen to stories. They become *caught up*, a phrase that can only be explained by another metaphor: stories get under people’s skin. Once stories are under people’s skin, they affect the terms in which people think, know and perceive” (p.48, emphasis in original). Furthermore as Mayer (2014) illustrates, “stories motivate our actions. When we act we are often to a great extent *enacting*, we are acting out the story as the script demands, acting in ways that are meaningful in the context of some story” (p.7, emphasis in original). Thus in relation to this thesis, the role of narrative in shaping people’s understanding of health and well-being, and experiences of illness and injury need to be explored.

2.3.1 Narratives of health and illness

The dominant narratives that circulate within society and culture influence our understanding of health and well-being (Frank, 2006). These stories circulating “out there” are extremely powerful narrative resources for framing experiences of health, disability, and illness. For example, they can reassure or scare people, increase awareness of a certain illness and disease or cause us to reject a specific intervention. As Frank (2006) asserts:

Health for any person is a fluid process of living with certain stories and taking on board some new stories, while leaving many competing stories to float in the river of not-for-me. For a community, health is the distribution of which people are caught up in which stories, where those stories come from, and what different stories do to the lives of those who are caught up in them, with what reverberating effects on who else (p.424).

For Gubruim and Holstein (2009), these stories are circulating in a “narrative environment”. A narrative environment can incorporate larger abstract socio-cultural environments as well as physical locations such as a rehabilitation hospital or physical activity rehabilitation centre (Perrier et al., 2013). Narrative environments play an important role in supporting specific narratives while disregarding and silencing others (Gubruim & Holstein, 2009). For example, the most socially acceptable narratives promoted in hospitals invite certain stories and behaviours from their patients, such as adhering to treatment regimens, while minimising alternative stories (Perrier et al., 2013).

The role of narrative as an approach to understanding disability as well as illness has grown in popularity since the 1980s when a number of influential scholars identified the importance of narrative in experiences of disability or illness (e.g. Bury, 1982; Ricoeur, 1984; Kleinman, 1988; Polkinghorne, 1988). An exploration of illness experience has highlighted how people use narrative to regain a sense of coherence following a life threatening event or unexpected crisis (Crossley, 2000). For example, Bury (1982) conceptualised chronic illness as a form of *biographical disruption* as the illness ruptures the “structure of everyday life” (p.169). This is because “when illness breaks our anticipated life paths, our narratives lose coherence and with it meaning and identity are also lost” (Papathomas et al., 2015, p.314). Thus, people use narrative to make sense of the disruption to their lives, such as when a SCI occurs, by trying to regain coherence to their story. This process of creating new stories to

provide coherence to a life story and give meaning to illness and injury has been conceptualised as narrative reconstruction (Crossley, 2000).

Through an in-depth and prolonged exploration of illness experience, Frank (2013) identified three broad narrative types that underpin stories of illness. These were restitution, chaos and quest. Frank proposed that the restitution narrative is the *metanarrative* of modern Western culture with a basic storyline of “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again.” (p.77). In stories of restitution, the ill or injured individual is seeking to regain their former selves. As Frank contends, “For the individual teller, the ending is to return to just before the beginning: ‘good as new’ or status quo ante. For the culture that prefers restitution stories, this narrative affirms that breakdowns can be fixed” (p.90). Chaos on the other hand is the opposite of restitution in that the plot of chaos imagines life never getting better:

Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernible causality. The lack of coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a “proper” story. But more significantly, the teller of the chaos story is not heard to be living a “proper” life, since life as in story, one event is expected to lead to another (Frank, 2013, p.97).

The quest narrative differs from both restitution and chaos in that the individual seeks to gain something positive from their illness experience. Accordingly, “quest stories meet suffering head on; they accept illness and seek to use it....What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained from the experience” (Frank, 2013, p.115).

2.3.2 A narrative approach to spinal cord injury, physical activity and hope

Frank’s (2013) narratives of illness have been drawn upon to interpret experiences of stroke (France et al., 2013), cancer (Simpson et al., 2014) and SCI (Smith & Sparkes, 2005; Perrier et al., 2013) to name just a few. Here, narrative research has also been influential in helping us understand hope. For example, in SCI, the restitution narrative follows the plot “yesterday I was able-bodied, today I’m disabled, but tomorrow I’ll be able-bodied again” (Smith & Sparkes, 2005, p. 1096). The restitution narrative acts on people to shape their experience of illness as the person following this plot is hopeful of, and may even expect, recovery. Indeed, Smith and Sparkes (2005) aligned the restitution narrative to concrete hopes of recovery from

SCI. In restitution stories concrete hopes are linked to technological or medical breakthroughs to restore the individual to their pre-injured self (e.g. via stem cell surgery). The danger of living by restitution is what happens when recovery is not forthcoming? As Frank (2013) warns “Restitution stories no longer work when the person is dying or when impairment remains chronic. When restitution does not happen, other stories have to be prepared or the narrative wreckage will be real” (p.94). Without another story to live by, individuals can be plunged into chaos. Individuals with SCI living in chaos live in despair and imagine life never getting better and therefore have lost all hope of a future worth living (Smith & Sparkes, 2005). On the other hand, people who frame their stories by the quest narrative are not actively seeking a cure from SCI. Rather, the quest narrative offers transcendent hope as an uncertain future is embraced as being full of exciting possibilities and tied to developing the self as a disabled person (Smith & Sparkes, 2005).

Understanding the types of narrative that people draw upon following illness and injury can also help us understand how these narratives shape their actions in relation to different types of PA. In relation to this thesis the focus of PA will be on leisure time physical activity (LTPA) rather than elite sport. LTPA is defined as an activity people chose to partake in their spare time such as exercising in the gym, playing recreational sport, or general wheeling (Martin Ginis et al., 2010a; Smith, 2013). Listening to the stories of people with SCI can enhance our understanding of their motivations to be physically active and what they are hoping to achieve. For example, narrative may be able to shed light into why some people seek to overcome a given barrier to exercise; whereas others are halted in their tracks. Theory-based determinants of LTPA have been useful in identifying constructs such as attitudes, self-efficacy, intentions and planning that influence LTPA behaviour in people with SCI (e.g. Latimer & Martin Ginis, 2005; Latimer et al., 2006; Arbour-Nicitopoulous et al., 2009). However the limitation with theory based approaches is that they only account for a small proportion of variance in LTPA behaviour (Perrier et al., 2013). In other words, these cognitive approaches to understand LTPA behaviour ignore the storied nature of human action.

To address the limitations with theory based approaches, Perrier et al. (2013) drew upon Frank’s illness narratives to explore why people with SCI engaged in specific types of LTPA. The authors identified that individuals who constructed their stories using the restitution narrative were motivated to engage in more functional LTPA opportunities in the hope of returning to a life that mirrored to one lived before SCI. In this instance LTPA was

used to restore function or maintain the body for a potential cure in the future. There was one individual in the study by Perrier et al. (2013) that constructed their story post-injury with the chaos narrative. This individual sought LTPA to temporarily escape chaos and preferred solitary LTPA experiences as exposure to others with SCI was an unwelcome reminder of the lost pre-injured self. In contrast, those individuals using quest were drawn to LTPA opportunities that allowed them to connect with and support others with SCI.

Accordingly, *different* narratives can *act on* individuals with SCI to engage with LTPA in *different* ways. The research by Perrier et al., (2013) additionally highlighted the importance of the narrative environment of LTPA opportunities for promoting and inhibiting certain types of stories. In relation to this project, the unique narrative environment of both the SCI centres and Neurokinex (described in chapters six to nine) will be important in influencing what narratives are most, and least, accessible to people. As Perrier et al. (2013) suggest, considering how the narrative environment affects what stories are valued, and what stories are inhibited, is an important next step for LTPA interventions. Furthermore, thoughts should turn to the important role other people play in promoting certain narratives over others. For example, the other people in this project include HCPs and health practitioners (e.g. the physiotherapists in the SCI centres and the trainers at Neurokinex), as well as friends, family and peers with SCI.

2.4 The PhD project: Rationale, aims and research questions

Drawing upon the current literature, this research has three main aims. Firstly, given the elevated levels of inactivity among people with SCI, this research aims to explore the barriers, benefits and facilitators of LTPA. This aim will be achieved through a systematic review and meta-synthesis of the qualitative literature on SCI and LTPA, an exploration of the role of LTPA in SCI rehabilitation, and a narrative examination of factors that impact participation at the LTPA initiative Neurokinex. Secondly, given the important role of hope in narratives of illness and injury in shaping experience and motivations to be physically active, this research aims to examine how hopes and expectations are managed. This aim will be explored with the physiotherapists in SCI rehabilitation and the trainers at Neurokinex. Thirdly, having identified a need for more effective LTPA promotion strategies, this research aims to propose improvements to LTPA promotion for people with SCI, HCPs in rehabilitation and health practitioners in the community. In line with the above aims, this research addresses the following key questions:

- 1) What does the published qualitative research literature contribute to our empirical knowledge of the barriers, benefits and facilitators of LTPA after SCI? (chapter three)
- 2) What do physiotherapists in SCI rehabilitation *perceive* about PA for people with SCI? (chapter six)
- 3) What do physiotherapists feel they *do* in relation to promoting PA? (chapter six)
- 4) How do physiotherapists manage hope and expectations in SCI rehabilitation? (chapter seven)
- 5) What are the barriers, benefits and facilitators of ABR for people with SCI? (chapters eight and nine)
- 6) What kinds of stories shape the clients' experiences of ABR, how do they do this and with what effects on hope? (chapter nine)
- 7) How are hopes and expectations managed in ABR? (chapter nine)
- 8) How can the knowledge generated inform policy and practice in order to improve the lives of people with SCI in relation to facilitating a more physically active lifestyle? (chapter ten)

2.5 Summary

In this chapter I have reviewed the literature pertaining to key underpinning theoretical and conceptual ideas relating to this research. I have described the models of disability and the challenges for rehabilitation professionals to adopt more conceptual models to understand the complexity of disability beyond the physical limitations proposed by the medical model. In addition I have highlighted the important role of rehabilitation and PA for the health and well-being of people with SCI and the need to understand hope within this context. Furthermore I have introduced narrative as a method for exploring experiences of SCI to understand what motivates people to be physically active. This research aims to increase our understanding of the factors that impact participation in LTPA for people with SCI and how hopes are shaped and managed within rehabilitation and in the community. Drawing upon these empirical findings, this research also aims to improve LTPA promotion and facilitate a more physically active lifestyle for people with SCI. The next chapter addresses the first aim by providing a more critical review of the literature on SCI to LTPA through a systematic review and meta-synthesis of this topic.

Chapter 3: Barriers, Benefits and Facilitators of Leisure Time Physical Activity for People with Spinal Cord Injury

3.0 Overview

In the literature review I presented a broad overview of the key conceptual topics relating to this research project. In this chapter, I present a more critical review of the literature by drawing upon meta-synthesis as a systematic and rigorous method to locate, critically appraise and synthesise the qualitative research on spinal cord injury (SCI) and leisure time physical activity (LTPA). The rationale for using the specific method of thematic synthesis is given, as well as a detailed report on the stages undertaken to identify the focus of the review, search for relevant papers, appraise their quality and synthesise the findings. The main section of this chapter comprises the results of the meta-synthesis which provide a more nuanced understanding of the factors that impact participation in LTPA for people with SCI. These results are then briefly discussed in light of how healthcare professionals (HCPs) could use this information to promote a more physically active lifestyle for the spinal cord injured population.

3.1 Introduction

Physical activity (PA) promotion was highlighted in the literature review (chapter two) as a significant and timely issue for the spinal cord injured community. Before any improvements to PA promotions can be instigated, the barriers, benefits and facilitators of being physically active for people with SCI need to be understood. As Vissers et al. (2008) highlighted, “To optimise the rehabilitation programme in persons with SCI after discharge with respect to a more physically active lifestyle, it is important to determine the barriers to and facilitators of physical activity after their discharge” (p.461). In other words, by understanding what factors constrain and promote PA in the SCI population, HCPs, governing bodies, rehabilitation centres and community organisations will be in a better position to support disabled people to be physically active for life. One way to rigorously deepen the understanding of barriers, benefits and facilitators of PA for people with SCI is through the systematic review of literature and meta-synthesis of qualitative research on this topic.

A meta-synthesis is “a rigorous and explicit research method which aims to locate, critically appraise and synthesise the findings of multiple studies pertaining to a specific research question” (Hammell, 2007, p.125). There are various reasons why a meta-synthesis is needed at this point in time. Firstly, this synthesis of qualitative evidence provides the opportunity to enrich understanding of the quantitative data on PA behaviour and inform evidence-based healthcare practice (Walsh & Downe, 2005; Hagger, 2013). Secondly,

qualitative research methods are able to identify relationships to PA that “emerged from people’s lived experience” of SCI (Fekete & Rauch, 2012, p.148). Thirdly, the psychosocial literature on Paralympic athletes including those with SCI has already been subjected to a systematic review (Jefferies et al., 2012), leaving a significant gap in the literature for a synthesis of data on SCI and participation in LTPA. By focusing on LTPA rather than elite sport, this chapter will be applicable to the wider SCI community. It will contribute original knowledge by not only drawing together work on LTPA, but also informing HCPs on LTPA promotion.

3.2 Methods

There are various methods for synthesising qualitative research that differ in their approach and output of the meta-synthesis depending on the research question (for further reading on types of review please see: Weed, 2006; Barnett-Page & Thomas, 2009; Grant & Booth, 2009; Gough et al., 2012). For the purpose of this research, the type of meta-synthesis used was *thematic synthesis*. The method of thematic synthesis was developed “out of a need to conduct reviews that addressed questions relating to intervention need, appropriateness and acceptability – as well as those relating to effectiveness – without compromising on key principles developed in systematic reviews” (Thomas & Harden, 2008, p.3). The process of meta-synthesis of qualitative data consists of five consecutive phases. These are as follows: identifying the focus of the review; identifying published papers relevant to the research question; appraising the studies for research quality; identifying and extracting the relevant data and summarising key themes from each paper; and comparison and synthesis of key themes into new concepts (Walsh & Downe, 2005; Hammell, 2007; Thomas & Harden, 2008; O’Connell & Downe, 2009).

3.2.1 Identifying the focus of the review

The first stage of a meta-synthesis is to develop a focused research question. The research question will then guide the search strategy used to locate the relevant literature in the next stage. In line with the research aims of this thesis, the purpose of this meta-synthesis was to a) systematically search and appraise the qualitative research on LTPA for people with SCI; b) synthesise knowledge from existing research regarding the barriers, benefits and facilitators to being physically active; and c) based on the results propose improvements to LTPA promotion in SCI for HCPs. The following research question (question 1 as noted in the literature review) was established: What does the published qualitative literature

contribute to our empirical knowledge of the barriers, benefits and facilitators of LTPA after SCI?

3.2.2 Identifying published papers and determining their relevance

The second phase of the meta-synthesis was to identify published papers relevant to the focus of the review on barriers, benefits and facilitators to LTPA in people with SCI. Published articles from January 2000 to December 2012 (time the meta-synthesis was conducted) were identified by searching the following databases: Medline, PsychINFO, PsycARTICLES, Scopus, SPORTSDiscus and World of Knowledge. Articles prior to 2000 were disregarded due to reduced hospitalisation periods for SCI and improved community facilities for wheelchair users over the last decade (Levins et al., 2004; Letts et al., 2011). Therefore studies from 2000 were more relevant to any future LTPA promotions. The search terms used related to SCI, qualitative research and LTPA to identify as many relevant published articles as possible:

- 1) Terms for SCI: ‘spinal cord injur*’ OR paraplegi* OR tetraplegi* OR quadraplegi*.
- 2) Terms for methodology: ‘qualitative research’ OR ‘focus group*’ OR interview* OR ethnograph* OR ‘participant observation*’ OR interpret* OR ‘life world*’ OR ‘lived experience*’ OR ‘grounded theory’ OR ‘content analysis’ OR ‘discourse analysis’ OR ‘thematic analysis’ OR ‘constant comparative’ OR ‘narrative analysis’ OR ‘conversation analysis’ OR hermeneutic* OR phenomenology.
- 3) Terms for leisure time physical activity: ‘leisure time physical activity’ OR ‘physical activit*’ OR ‘physically active’ OR exercise OR sport* OR fitness OR ‘active living’ OR training OR leisure.

The literature search identified 2878 citations from the six databases after the removal of duplicates and non peer-reviewed resources (Figure 3.1). An additional hand search was conducted of relevant journals and papers to compensate for any insufficient database indexing (Walsh & Downe, 2005; Hammell, 2007). These were identified through reference lists, bibliographies, citation searching and contact with experts.

Based on the research question, primary inclusion criteria for this study were as follows: a) a qualitative research methodology was used, b) the research focused on a SCI population, c) the group sampled in this work were discharged from a SCI unit and living in the community, d) the research contained data on at least one of the factors impacting participation in LTPA (e.g. barriers, benefits, facilitators), e) the empirical data was published

in a peer review journal, and f) the full text was in English. Studies were excluded if: a) the sample was not exclusively spinal cord injured, b) the research relied solely on third party evidence (e.g. therapist, carer, partner), c) the participants were under the age of 18, d) the participants competed in elite sport (i.e. Paralympic or International athletes), e) the studies were outside of the Western world, and f) the primary methodology was quantitative.

In line with a meta-synthesis, the papers were first appraised based on the relevance of their title to the focus of the review. In total 2399 papers were removed because the title was overtly unrelated to the research question. The abstracts of the remaining 479 papers were then read and either accepted or rejected based on the inclusion and exclusion criteria. Through this process 415 papers were removed. Where the abstract suggested potential relevance to the research question, or did not provide enough information to apply the inclusion/exclusion criteria, the full text of the article was read (Hammell, 2007). From the remaining 64 papers read in full, another 46 were removed due to the exclusion criteria. The final 18 papers were identified as being relevant to the review question and no further papers were identified through searching the reference lists of these papers. To ensure the transparency of this process, a record of the decision making process is illustrated below in the form of a PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart (Moher et al., 2009) (Figure 3.1).

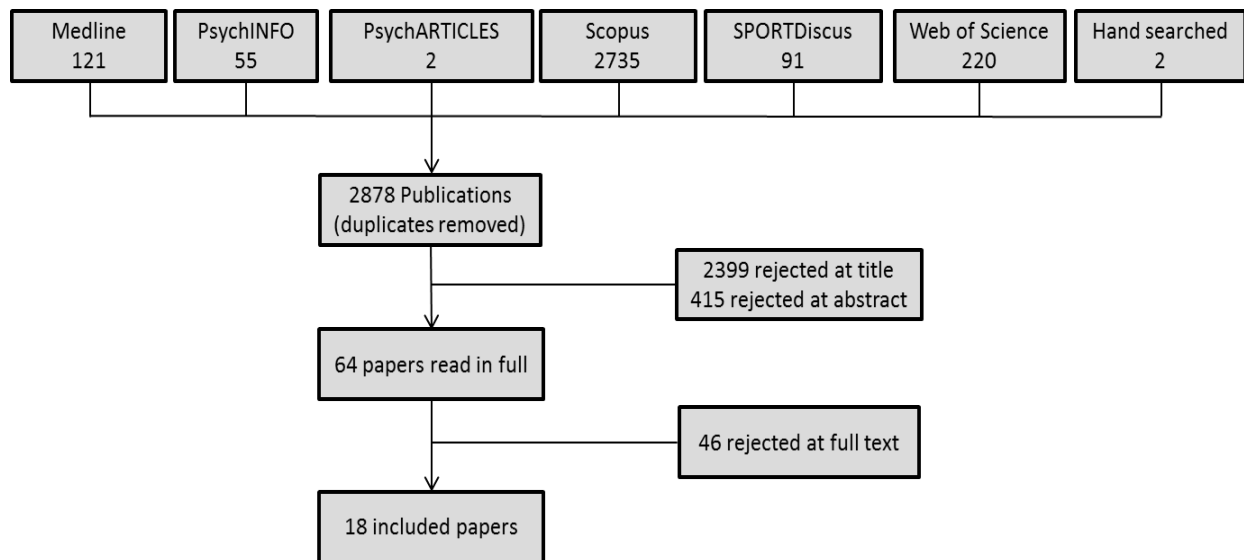


Figure 3.1: Systematic literature search and exclusion of papers

Although papers had to employ a qualitative methodology, papers were not excluded according to the specific type of qualitative methods used. As expanded upon by Walsh and

Downe (2005), “in the qualitative paradigm, which sees truth as multiple, and knowledge as constructed, it is legitimate to include a variety of approaches in a meta-synthesis” (p.207). This is supported by Sparkes and Smith (2014) who state that qualitative research is an umbrella term that comprises many small communities of multiple traditions and multiple methods. All this said, if papers were of a mixed method design, primarily quantitative with a small section of qualitative research, then they were excluded (Hammell, 2007). The final 18 studies (Table 3.1) included a wide variety of participants in terms of their age, time since injury and level of injury including both complete and incomplete SCI. Some papers focused on LTPA, whereas other papers explored one aspect of living with SCI that referred to being physically active. These references were brief in places but were included in the meta-synthesis because they added knowledge on the barriers, benefits and facilitators to LTPA for community-dwelling people with SCI.

3.2.3 Quality of the research

The meta-synthesis involved synthesising research findings from multiple qualitative studies comprising of a variety of research methods. Appraising the quality of these studies has been proposed as a vital stage in the process to avoid including studies with methodological deficiencies (Hammell, 2007; Thomas & Harden, 2008; O’Connell & Downe, 2009). To compensate for differences in methodology, Garside (2014) recommended that papers in qualitative systematic reviews should be appraised based on criteria of trustworthiness (epistemological aspects), theoretical considerations and practical (technical) considerations. Garside suggests that this method allows for “careful consideration of the study within its own terms” (p.11). As part of an ongoing list of criteria, examples of considerations included:

- Trustworthiness – Is the design and execution appropriate to the research question? How well supported by the data are any conclusions?
- Theoretical considerations – Does the report connect to a wider body of knowledge or existing theoretical framework? If so, is this appropriate? Does the paper develop explanatory concepts for the findings?
- Practical considerations – Does the study usefully contribute to the policy question? Does this study provide evidence relevant to the policy setting? Does this study usefully contribute to the review?

Table 3.1: Summary of review papers

Paper	Aim	Sample	Country	Data collection	Design/Analysis
Bowden et al (2008)	Describe a multidimensional approach to examine functional recovery after a therapeutic intervention	N = 1 (1 man) Age = 59 Injury = C level SCI-i Time since injury = 1.3 years	USA	Semi-structured interviews	Qualitative interviewing/thematic analysis
Chun & Lee (2010)	Explore the role of leisure in experience of posttraumatic growth for people with SCI	N = 15 (10 men) Age range = 27-58 Injury = C, T level Time since injury = 1-34 years	USA	Open-ended interviews	Grounded theory/thematic analysis
Dickson et al (2011)	Explore lived experiences of SCI	N = 17 (14 men) Age range = 26-62 years Injury = C level Time since injury = 1.4-32 years	UK	Semi-structured interviews	Interpretive phenomenological analysis (IPA)
Hannold et al (2006)	Examine experiences locomotor training in persons with incomplete SCI	N = 8 (7 men) Age range = 22-73 years Injury = C, T level SCI-i Time since injury = 0.25-3 years	USA	Semi-structured interviews, observations of participants	Grounded theory/thematic analysis
Kehn & Kroll (2009)	Explore barriers and facilitators of exercise after SCI	N = 26 (16 men) Age range = 23-74 years Injury = C, T level SCI-i/c Time since injury = 1-32	USA	Semi-structured interviews	Ethnographic approach/content analysis
Letts et al (2011)	Explore preferred methods of PA communication to people with SCI	N = 16 (14 men) Age = mean 52.4 years Injury = 6 paraplegic, 10 tetraplegic Time since injury = mean 15.87 years	Canada	Focus groups	Phenomenological approach/content analysis
Levins et al (2004)	Explore experiences of individuals with SCI participating in PA	N = 8 (5 men) Age = mean 42 years Injury = T level SCI-i/c Time since injury = 2-27 years	Canada	Semi-structured interviews	Ethnographic approach/thematic analysis
Lofgren & Norrbrink (2012)	Explore strategies and treatments used to for pain management in people with SCI	N = 18 (11 men) Age range = 28-66 years Injury = C, T, L level Time since injury = 3-31 years	Sweden	Diary, interviews	Grounded theory/content analysis
Manns & Chad (2001)	Determine themes that represent QOL for people with SCI	N = 15 (9 men) Age range = 22-63 years Injury = 8 paraplegic 7 quadriplegic, SCI-c Time since injury = mean 13 years	Canada	Semi-structured interviews	Ethnographic approach/thematic analysis

Martin et al (2002)	Explore perceived benefits and barriers to exercise to better understand exercise motivation among people with SCI	N = 15 (11 men) Age range = 19-49.5 years Injury = unknown Time since injury = unknown	Canada	Focus groups, flip chart notes	Focus group discussions
O'Brien et al (2008)	Explore post injury leisure participation for individuals with acquired SCI	N = 18 (unknown) Age range = 31-60 years Injury = 7 paraplegic, 11 tetraplegic Time since injury = 8-35 years	Canada	Semi-structured interviews	Modified grounded theory/thematic analysis
Pentland et al (2002)	Examine the impact of aging in women with SCI	N = 29 (0 men) Age range = 35-70 years Injury = C, T, L level Time since injury = 3-38 years	Canada	Focus groups, interviews	Explanatory models, thematic analysis
Price et al (2011)	Examine the life satisfaction and occupational and social participation of SCI individuals	N = 11 (6 men) Age = unknown Injury = 5 paraplegic, 6 tetraplegic SCI-i/c Time since injury = 1-5 years	USA	Semi-structured interviews	Narrative analysis
Semerjian et al (2005)	Assess effects of adapted exercise on QOL and body satisfaction in people with SCI	N = 12 (8 men) Age range = 18-51 years Injury = C, T level Time since injury = 1-30 years	USA	Semi-structured interviews, field notes	Grounded theory
Smith (2013)	Examine health narratives told by men with SCI	N = 17 (17 men) Age = unknown Injury = unknown Time since injury = unknown	UK	Life history narrative interviews, field work observations	Narrative analysis
Stephens et al (2012)	Explore perceived benefits and barriers to sports participation in people with SCI	N = 7 (6 men) Age range = 26-49 years Injury = C, T level SCI-i/c Time since injury = 4-33 years	UK	Semi-structured interviews	Inductive generalisation
van de Ven et al. (2008)	Identify strategies used by people with high cervical SCI to function autonomously	N = 8 (5 men) Age range = 27-55 years Injury = C level Time since injury = 3-32 years	The Netherlands	Semi-structured interviews	Qualitative research/thematic analysis
Wahman et al (2006)	Identify factors that promote participation in PA among people with SCI	N = 16 (12 men) Age range = 21-61 years Injury = 8 paraplegic, 8 quadriplegic Time since injury = 2-41 years	Sweden	Semi-structured interviews	Qualitative multiple case study design/cross-case method analysis
			<i>Note.</i> C = cervical; T = thoracic; L = lumbar; SCI-i = incomplete SCI; SCI-c = complete SCI.		

As Garside (2014) advocates, these lists are not prescriptive but intended to be indicative of research quality³. When considering the quality of each paper under these three headings the following were noted. Firstly, trustworthiness was assessed using the above criteria and in all cases each paper had a design appropriate to the research question and used data to support their concluding statements. Secondly, theoretical considerations were difficult to judge in instances where the papers (Martin et al., 2002; O'Brien et al., 2008) were exceptionally short in length. I therefore decided that studies should not be rejected based on the word limits imposed by the journal. Thirdly, for practical considerations, I found that ultimately all papers usefully contributed to the review. Using these guidelines no papers were rejected in the appraisal process.

3.2.4 Summarising themes

Drawing upon the principles of thematic synthesis, the fourth stage involved extracting data, coding the text and developing themes. In the first instance, the final studies were read and re-read to become familiar with the findings in each study. Following Thomas and Harden (2008), the process of extracting data was carried out by taking all text labelled 'results' or 'findings' that pertained to the research question. This data was then compiled into lists of barriers, benefits and facilitators to LTPA as mentioned within each paper. Barriers referred to the reasons why people did not participate in PA, discontinued PA or their negative experiences with PA. The benefits included the positive responses and any perceived advantages from participation in LTPA. Facilitators were recorded as factors that allowed people to participate in LTPA or the motivational reasons as to why they started and continued participation in LTPA. The difference between a benefit and a facilitator is of importance because "while perceived health benefits may act as a facilitator of continued exercise, it would seem that only the anticipation of such benefits would facilitate initial engagement" (Kehn & Kroll, 2009, p.175).

The next step of this phase involved coding the data line by line according to both its meaning and context. Coding the data allows for *translation*, which in this context refers to the "process of taking concepts from one study and recognising the same concepts in another study, though they may not be expressed using identical words" (Thomas & Harden, 2008, p.3). Once the data was coded, the next step was to look for similarities and differences in the

³ The issue of judging quality and rigour within a meta-synthesis is reflective of the larger debate around judging qualitative inquiry in general. This issue is discussed in more detail within the methodology chapter (chapter four) and addressed in relation to conducting a meta-synthesis in the methodological implications section of the main discussion (chapter ten).

codes and group them together into descriptive themes. The summarising themes process allowed for factors raised by the participants from their direct quotes and the themes interpreted by the researchers to be identified. The factors did not have to be explicitly conceptualised across all participants in the original research findings to be included. This point is important because issues of minor concern in one study may have strengthened importance if they occurred across all studies (Hammell, 2007). In cases where there were other participants included in the study (caregivers, therapists, etc.) only quotes or themes that were from individuals with SCI were included.

3.2.5 Conceptual synthesis

The final stage of the meta-synthesis was to generate analytical themes through interpretation and conceptual synthesis. A key feature of the method of thematic synthesis is its clear differentiation between generating ‘data-driven’ descriptive themes and generating ‘theory-driven’ analytical themes. It is in this final stage that the defining characteristic of a meta-synthesis is achieved. This characteristic is the notion of ‘going beyond’ the findings of the original studies to generate additional concepts and analytical themes (Thomas & Harden, 2008). In this stage, the descriptive themes in the lists of barriers, benefits and facilitators to LTPA were compared and synthesised into new concepts. This iterative process involved grouping the individual factors under unifying labels and drawing relationships to compare and identify themes into general categories (Walsh & Downe, 2005; Hammell, 2007).

An analysis of the primary data presented in each paper resulted in the identification of similar themes across the review papers that could be synthesised into key concepts. The synthesised concepts that emerged from the original data were not reduced to themes that were only present across all studies. As Walsh and Downe (2005, p.208) explain, this is because synthesising data is “not to do with distilling out a core meaning or reducing down related categories so that they can be placed under an umbrella of some all-encompassing theory or explanation”. Analysing data in a thematic synthesis should aim to preserve the meaning from the original text (Thomas & Harden, 2008). Trying to force a homogenous fit between all studies does not follow the interpretivist epistemology of qualitative research (Weed, 2008) (see chapter four). Many of the themes and final concepts identified were not mutually exclusive as a barrier, benefit or facilitator of LTPA. However, for ease of representation, the themes were illustrated as separate entities. This said, the relationships between the themes are explored in the subsequent discussion.

3.3 Results

The results of the meta-synthesis revealed eight overarching concepts that acted as barriers, benefits or facilitators of LTPA participation in people with SCI (Table 3.2). These were: 1) well-being; 2) environmental influences; 3) physical body; 4) body-self relationship; 5) physically active identity; 6) knowledge on LTPA; 7) restitution narrative; and 8) perceived absences.

Table 3.2: Concepts and themes and the papers in which they were found

Concept	Theme	Papers
Well-being	Subjective well-being	1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 14, 15, 16, 17, 18
	Psychological well-being	2, 5, 7, 11, 12, 14, 15, 16, 18,
	Social well-being	5, 6, 7, 10, 13, 14, 15, 16, 17, 18
Environmental issues	Material	3, 5, 7, 9, 10, 11, 12, 15, 16, 17, 18
	Geographical	5, 15, 16, 18
	Social support	1, 2, 5, 6, 7, 10, 11, 13, 14, 15, 16, 17, 18
Physical body	Biological impairment	4, 5, 8, 11, 12, 16, 17
	Biological improvement	1, 2, 5, 8, 9, 10, 11, 12, 14, 15, 16
	Illness prevention	5, 8, 9, 11, 14, 15, 16, 18
	Health maintenance	5, 9, 14, 15, 18
Body-self relationship	Disrupted body-self	4, 5, 7, 10
	Reintegrated body-self	4, 5, 7, 9, 10, 13, 14, 15, 16
	Disabled Identity	4, 7, 10, 13, 14, 15, 16, 17, 18
	Body-self compassion	15
Physically active identity	Physically active identity	2, 7, 8, 11, 13, 14, 16
	Development of active identity	2, 5, 7, 13, 14, 15, 18
	Continuation of active identity	2, 5, 7, 11, 18
Knowledge of LTPA	Lack of information	5, 6, 7, 10, 12, 15, 16
	Healthcare professionals	5, 6, 7, 10, 15, 16, 17
	Gaining information	6, 7, 11, 13, 15, 16, 18
Restitution narrative	Recovery	1, 2, 4, 10, 14
	Normative activity	14
Perceived absences	Lack of motivation	5, 6, 7, 8, 9, 10, 12, 15
	Lack of time	5, 6, 9, 10, 11, 12, 16
	Rejection of disability sport	5, 7, 15, 16
<i>Note.</i> 1 = Bowden et al. (2008); 2 = Chun & Lee (2010); 3 = Dickson et al. (2011); 4 = Hannold et al. (2006); 5 = Kehn & Kroll (2009); 6 = Letts et al. (2011); 7 = Levins et al. (2004); 8 = Lofgren & Norrbrink (2012); 9 = Manns & Chad (2001); 10 = Martin et al. (2002); 11 = O'Brien et al. (2008); 12 = Pentland et al. (2002); 13 = Price et al. (2011); 14 = Semerjian et al. (2005); 15 = Smith (2013); 16 = Stephens et al. (2012); 17 = van de Ven et al. (2008); 18 = Wahman et al. (2006).		

3.3.1 Well-being

The results of the meta-synthesis revealed that an individual's well-being impacted upon their engagement in LTPA. Well-being generally refers to "optimal psychological function and experience" (Ryan & Deci, 2001, p.142). There are two distinct perspectives of well-being

that originate from different philosophical traditions. The first of these is subjective well-being (SWB) which is founded from the hedonic perspective that well-being consists of life satisfaction and happiness (Keyes et al., 2002). The second view is psychological well-being (PWB) from the eudaimonic perspective which relates well-being to psychological growth and development (Ryan & Deci, 2001; Keyes et al., 2002) (see chapter two).

A person's SWB involves their perceived happiness and satisfaction with life (Ryan & Deci, 2001; Keyes et al., 2002). The research indicated lower levels of SWB as a barrier to being physically active. These included: depression, lack of self-confidence, embarrassment and too much emotional pressure to deal with PA (Martin et al., 2002; Levins et al., 2004; Semerjian et al., 2005; Stephens et al., 2012). On the other hand, participating in LTPA heightened SWB: "It helped the more complicated emotional adjustment, and ...so that was a tremendous vehicle to build self-esteem, self-confidence and feel capable as a person" (Levins et al., 2004, p.502). Physical improvements in mobility and capability also positively influenced SWB (Martin et al., 2002; Bowden et al., 2008). Improvements in SWB acted to motivate people with SCI to continue being physically active. Indicators of enhanced SWB that facilitated LTPA were experiences of general positive emotions that led to an increase in life satisfaction (Semerjian et al., 2005; O'Brien et al., 2008; Smith, 2013). A strong facilitator of engagement in LTPA amongst the participants in the studies synthesised was the ability to improve and maintain independence: "The driving force when it comes to the bottom line, is being as independent as possible and not having to ask for help" (Wahman et al., 2006, p.485).

Participation in LTPA also enhanced PWB as indicated through psychological growth and development. PWB is concerned with dimensions of human flourishing and the "actualisation of human potential" (Ryan & Deci, 2001, p.143). Signs of improved PWB included the following: an improved outlook in life (Semerjian et al., 2005), experiencing posttraumatic growth (Chun & Lee, 2010) and finding a purpose in life (Stephens et al., 2012). Whilst the two constructs of well-being are distinct, there are overlapping and related components (Keyes et al., 2002). The results of the meta-synthesis suggest that SWB and PWB do influence each other. For example, feelings of positive emotion occurred from having a purpose in life as illustrated in the data: "That's huge for me. It's meant I've been able to work in a demanding job and get my self-worth back as a man" (Smith, 2013, p.115). Social well-being (social WB) is a sub component of PWB that indicates perceived flourishing and function in an individual's social life (Keyes, 1998). Social WB was

additionally enriched through LTPA with indicators of improved social participation and integration (van de Ven et al., 2008; Price et al., 2011; Stephens et al., 2012).

As well as lowered SWB, participants indicated a reduction in social WB as a barrier to participation in LTPA. Feelings of social exclusion stemmed from fear: “Fear of being out there in public. I kind of shut myself off to the world” (Stephens et al, 2012, p.2067). Participants revealed how, based on their impairments alone, they perceived negative attitudes from the general public (Levins et al., 2004; van de Ven et al., 2008). In contrast, flourishing in both personal and social life experiences through being physically active, facilitated future LTPA participation (Semerjian et al., 2005). Making a valued contribution to society was another motivational factor to participate in LTPA. One example of this was becoming a role model for others with SCI (Wahman et al., 2006). Being dependable, not only as a teammate, but as a family member (Wahman et al., 2006) also facilitated LTPA: “That’s why I go to the gym, to do this with my son, to be a proper dad” (Smith, 2013, p.115).

3.3.2 Environmental influences

The material, geographical and social environment of individuals with SCI substantially impacted upon their engagement in LTPA. In line with the social relational model of disability that built upon the social model (see chapter two), common themes amongst the final studies in the meta-synthesis were the aspects of the material environment that acted as a barrier to participation in LTPA. These included a lack of both personal and communal resources, inadequate finances and the high cost of participating in wheelchair sport (Manns & Chad, 2001; Pentland et al., 2002; Wahman et al., 2006; Kehn & Kroll, 2009; Stephens et al., 2012; Smith, 2013). Even when there were communal exercise facilities, participants came across obstacles such as accessibility and availability (Levins et al., 2004; Wahman et al., 2006; Kehn & Kroll, 2009; Smith, 2013). A lack of facilities in some instances resulted in feelings of frustration at the inability to maintain fitness levels gained in hospital. As one participant expressed: “Obviously not having the facilities to train your fitness levels drop and you can’t do exercises (...) so the exercise sheet you’ve got is a total waste of space” (Dickson et al., 2011, p.468). On the other hand increased access and availability of facilities, or adequate funding, facilitated participation in LTPA: “To finally have the chance to work out with equipment that’s designed for us and in a place that’s laid out in such a way that I can move around and do what I want to do is awesome” (Martin et al., 2002, p.40).

Aspects of the geographical environment that impacted upon LPTA included the weather and transport. Cold wet weather coupled with long distances to facilities, limited transport and parking, all prevented people from being physically active (Wahman et al., 2006; Kehn & Kroll, 2009; Stephens et al., 2012; Smith, 2013). Whereas in the summer months the dry, and most importantly, warm weather facilitated LPTA participation.

In line with the social relational model of disability that highlights the importance of relationships in restricting activities, a perceived lack of social support was another social environmental barrier that prevented people with SCI from being physically active. This is a separate theme from social well-being, as in this context we are referring to a person's social environment which includes other people as a physical resource to be physically active. Social support in this instance includes emotional support, advice and guidance, and more tangible support such as physical assistance and providing transport (Cohen et al., 2000). The results of the meta-synthesis highlighted that a lack of personal assistance resulted in being dependent upon others to exercise (Levins et al., 2004; Kehn & Kroll, 2009; Stephens et al., 2012). Social support was therefore crucial in facilitating LTPA. Social support networks, as relational networks that can facilitate or restrict activities as suggested by the social relational model, included: friends, family, peers, disability groups and activity centres (Martin et al., 2002; Levins et al., 2004; Price et al., 2011; Smith, 2013). Moreover, participating in LTPA with peers provided a sense of realisation about what could be achieved with SCI: "Seeing other people basically other people with the same level injury you have, see what they can do and you just sit there and you go wow – if he can do that, maybe I can too" (Letts et al., 2011, p.133). Additionally, engaging in LTPA provided the opportunity for incidental learning to occur from people with similar injuries and impairments (Chun & Lee, 2010; Stephens et al., 2012). The importance of this benefit from LTPA was reflected in the data: "At the end of the quad rugby session we always hang around for a while at the bar. And that is the time for me to ask questions and get answers from the others...And those guys together know more than any rehabilitation doctor will ever know" (van de Ven et al., 2008, p.253).

3.3.3 Physical body

SCI has a significant impact on the physical body (see chapter two). Biological impairments including loss of bodily control, fatigue and secondary health conditions all contributed to a lack of LTPA (Pentland et al., 2002; Hannold et al., 2006; van de Ven et al, 2008; Stephens et al., 2012). These reflect the lived experiences of an impaired body from the social relational model of disability (Smith and Perrier, 2014). Participation in LTPA was a barrier in itself, as

for some people with SCI this resulted in further injury and pain (O'Brien et al., 2008; Löfgren & Norrbrink, 2012). Importantly, many of the biological impairments that deterred people from being physically active were improved through regular LTPA. These physical health benefits included increased strength, mobility, fitness and balance (Martin et al., 2002; Bowden et al, 2008; Kehn & Kroll, 2009, Stephens et al., 2012), reducing the effort required for activities of daily living (ADL) and secondary medical conditions (Semerjian et al., 2005; Kehn & Kroll, 2009). Moreover, a significant health benefit from participation in LTPA was that an alternative pain management technique to drug therapy was provided (Bowden et al., 2008; Kehn & Kroll, 2009; Löfgren & Norrbrink, 2012). Different forms of LTPA were reported to control and decrease pain levels: "When I exercise, I don't get so many spasms and it (pain) changes from a stinging to a tingling" (Stephens et al, 2012, p.2066).

These health benefits furthermore acted to facilitate LTPA with the aim to maintain health and prevent further illness. Taking responsibility for personal health after SCI contributed towards being physically active: "since leaving rehab I've felt I oughta take care of my health, physical and mental health" (Smith, 2013, p.115). Fear of health deterioration from weight gain and secondary health conditions additionally facilitated people with SCI to remain physically active (Manns & Chad, 2001). This was evident in the data: "I still do it (exercise). Partially out of fear. I don't want to get any worse..." (Kehn & Kroll, 2009, p.173).

3.3.4 Body-self relationship

A disruption to people's body-self relationship prevented them from being physically active, especially immediately post injury (Stephens et al., 2012). The loss of an able-bodied identity was coupled with a struggle to accept a new body and identity: "I don't think anybody really starts to get used to life in a wheelchair within the first couple of years... most people tend to take a few years to really get comfortable with what's happened and kind of come to terms with it" (Levins et al., 2004, p.501). This uncertainty regarding the body was reflected through both frustration and disappointment with current abilities, and a fear of PA causing more bodily damage (Martin et al., 2002; Hannold et al., 2006; Kehn & Kroll, 2009).

A benefit of being physically active was that it provided the opportunity to re-establish and re-integrate the body-self relationship (Levins et al., 2004). A sense of body-self compassion was developed through LTPA participation: "I like exercising as I feel I'm looking after my body, I'm being kind to it now, not hating it like I did straight after the

accident, which is part of adjusting to the injury” (Smith, 2013, p.114). Furthermore another benefit of being physically active was that people with SCI were able to redefine their identity (Martin et al., 2002; Stephens et al, 2012). This integration of the body-self relationship facilitated continued exercise behaviour as stereotypical disabled identities were challenged: “I thought people in wheelchairs with a disability were really disabled people. And I had to redefine that in my head... It was a steep learning curve” (Levins et al., 2004, p.501). Interestingly, participating in sport was a medium that enabled the wheelchair to become a component of a sense of self: “But, when you’re playing rugby you’re working with the wheelchair so intensively, it feels like the wheels become your legs, and you overcome your fears” (van de Ven et al., 2008, p.254).

3.3.5 Physically active identity

Developing and embodying a physically active identity, either through sport or exercise, was both a benefit and a facilitator of LTPA. Sport, competition and athletic performance became central to some participants’ lives (Chun & Lee, 2010; Stephens et al, 2012). This physically active identity was also a reason to continue with LTPA participation and became a facilitator. For some participants remaining physically active after SCI was important as they were heavily involved in sport and exercise before their injury (Levins et al., 2004; O’Brien et al., 2008). These individuals were continuing with an identity they had previously embodied: “Well it (the injury) changed how I exercised... It didn’t change the fact that I knew I had to keep my body fit and as young as I could” (Kehn & Kroll, 2009, p.172). New physically active identities were developed as a result of the perceived benefits of LTPA participation: “Before I got my injury I was very uninterested in sport... Already, when I was still in the hospital I decided and realised it was up to me (to be physically active), but then it was more of a fight for a worthwhile life” (Wahman et al., 2006, p.486).

3.3.6 Knowledge on LTPA

The meta-synthesis revealed that not having knowledge on how and where to exercise was a barrier to being physically active in the community. The participants expressed that information on LTPA specifically for people with SCI was difficult to find (Martin et al., 2002; Pentland et al., 2002; Levins et al., 2004; Kehn & Kroll, 2009; Letts et al., 2011). Additionally, research reported there was a dearth of information available regarding LTPA from HCPs. Some participants commented on how HCPs focused on ADL and did not actively encourage LTPA (Levins et al., 2004; van de Ven et al, 2008; Letts et al., 2011). There was evidence that HCPs were unaware of suitable LTPA opportunities specifically for

SCI, as one participant was told: “well...umm... I don’t know where to send you. Have you looked online?” (Kehn & Kroll, 2009, p.174).

Acquiring the knowledge on where and how to be physically active facilitated LTPA participation for people with SCI. Information was gained through exposure to activities, media resources and interaction with peers (Levins et al., 2004; Wahman et al., 2006; O’Brien et al., 2008; Price et al., 2011; Stephens et al., 2012; Smith, 2013). Some HCPs were able to facilitate LTPA by distributing information about relevant activities from other patients with SCI: “They listen to our stories, our crazy stuff and all this...so that’s how they pass (it on)” (Letts et al., 2011, p.132).

3.3.7 Restitution narrative

The restitution narrative is a common storyline that projects the hope for recovery or cure after illness or disability (Frank, 2013). In SCI, the restitution narrative follows the plot of “Yesterday I was able-bodied, today I’m disabled, but tomorrow I’ll be able-bodied again” (Smith and Sparkes, 2005, p.1096) (see chapter two). The studies in the meta-synthesis that involved locomotor training, or other exercises with elements of standing and walking suggested restitution in action. Restitution was perceived as a benefit of LTPA as exercise machines that mimicked walking evoked strong emotions about the former self: “That was an amazing feeling. It gave you some dignity back” (Semerjian et al., 2005, p.102). In this case standing and walking were representative of both normative and desirable activities associated with a ‘momentary return’ to one’s former body.

Restitution as a facilitator was concerned with engaging in LTPA in the hope of recovery. Symptoms from exercise such as discomfort, soreness, spasms and muscle cramps were seen as signs of nerve regeneration and recovery from SCI (Semerjian et al., 2005; Hannold, et al., 2006; Chun & Lee, 2010). Another aim of keeping physically active was to be prepared for treatment in case of a cure: “One of the reasons why I try to keep my body in shape is because the thought that if in my lifetime there is a cure, I wanna be first in line. And I feel like if I have maintained my health then I would be a good candidate for that” (Semerjian et al., 2005, p.102). As signalled in this quote, the restitution narrative is connected to and fuelled by the medical model (see chapter two). In so doing, despite the problem identified in the literature review, the medical model is promoted. It remains alive in how disability and LTPA is understood.

3.3.8 Perceived absences

There were a collection of perceived absences that acted as a barrier to being physically active including a lack of time, energy and motivation. For example, following SCI, the time needed for ADL increased. Subsequently, less time was available to engage in LTPA (Martin et al., 2002; Letts et al., 2011; Stephens et al., 2012). A lack of time coupled with a lack of energy left people without the motivation to exercise: “It’s always a challenge to find enough time... the energy that work takes and with the energy that... just meeting your basic needs... there’s hardly any time left just to exercise” (O’Brien et al., 2008). For some participants exercise was simply not an important consideration in life (Kehn & Kroll, 2009). The perceived limited return, compared to the physical investment required to exercise, also contributed to a lack of PA (Löfgren & Norrbrink, 2012). This impacted upon motivation as shown in the data: “It just takes too much time and too much effort and I don’t think the benefits outweigh the costs” (Kehn & Kroll, 2009, p.172).

The findings of the meta-synthesis revealed that there was a lack of motivation and interest from some participants to engage in disability sport in particular. There were various reasons for this. Some participants expressed disappointment in the wheelchair versions of able-bodied sports: “I tried to play tennis in a wheelchair and I hated it. It wasn’t the same game” (Kehn & Kroll, 2009, p.172). Additionally, disability sport was not seen as inclusive for able-bodied friends (Stephens et al., 2012). Lastly, some women found it difficult to participate with men as they were in the minority (Levins et al., 2004), and some men rejected disability sport as they associated it with unhealthy masculine behaviour (Smith, 2013).

3.4 Discussion

The purpose of the meta-synthesis was to gather existing knowledge on the barriers, benefits and facilitators of LTPA among people with SCI. This is the first synthesis of qualitative research on LTPA and SCI and, as stressed in the final chapter, contributes original knowledge by revealing a deeper understanding of the complexities within the factors that impact LTPA participation. Additionally this meta-synthesis helps to bridge the gap between academic research and practice (Backus et al., 2013) by proposing improvements to LTPA promotion for HCPs. In order to successfully promote a physically active lifestyle, HCPs need to consider the following points:

Firstly, the relationships between the barriers, benefits and facilitators of LTPA need to be identified. An important finding from the results was that many of the barriers to LTPA were actually reduced as a result of being engaged in regular sport and exercise. Furthermore, the benefits from LTPA participation provided the motivation to continue to be physically active. Improvements of the physical body in the reviewed studies facilitated future LTPA engagement as individuals strived to maintain their health and prevent further illness. Maintaining independence and avoiding secondary health conditions was of paramount importance. This result was in contrast to Williams (2000) who proposed that further functional loss and secondary health conditions may be experienced as ‘normal’ rather than disruptive to people with chronic illness and impairment. The synthesised results however supported more recent explorations into illness narratives. Larsson and Grassman (2012) proposed that the risk of further physical deterioration may be just as critical and disruptive even years after living with a chronic condition. Participants exercised to avoid future bodily and functional loss as it was anticipated to lead to undesirable outcomes such as a loss of independence and subsequent decreases in both SWB and PWB.

Secondly, HCPs need to recognise that a disabling injury such as SCI can result in a parallel disruption of a person’s body-self relationship. A disruption to the sense of self due to the onset of illness and injury has, as noted in chapter two, been conceptualised as biographical disruption and is associated with pain, suffering and feelings of depression (Bury, 1982). Disruptions to the sense of self, characterised by an uncertainty of current physical abilities, frustrations with performance and a loss of identity since acquiring an SCI, acted as barriers to being physically active. Sport and exercise was beneficial in the meta-synthesis as a vehicle with which people were able to re-integrate their body-self relationship and re-define their identity. For others however SCI did not necessarily result in disruption. Individuals who were able to continue with a previously embodied physically active identity prior to SCI experienced biographical continuity of this identity (Williams, 2000).

Thirdly, HCPs need to deliver effective health promotion through LTPA including the benefits of LTPA, combined with information on where and how to exercise. As with other physical disabilities (Saebu, 2010; Martin Ginis et al., 2012; Mulligan et al., 2012; Cowan et al., 2013), the meta-synthesis revealed a lack of knowledge about where and how to exercise as a significant barrier to LTPA. When HCPs were not able to provide this information, people with SCI turned to their peers for advice and guidance on LTPA. Disability groups and activity centres provided social support that facilitated inspiration, encouragement to be

physically active and incidental learning about life with SCI. As Mazanderani et al. (2013) explains, the stories told by people with real life experiences are of value because they contain an “embodied source of knowledge” (p.897). In other words, people are more likely to value the advice given to them from peers because this knowledge comes from the lived experience of SCI of having and being an impaired body. Additionally, this information is sometimes of greater value than “disembodied medical knowledge” (Mazanderani et al., 2013, p.896). Due to the difficulties of disseminating LTPA guidelines for people with SCI, providing opportunities for peers as credible messengers to share stories may be another way to more effectively promote healthcare messages (Gainforth et al., 2013).

3.5 Overview

By synthesising existing qualitative knowledge, this chapter provides a deep understanding of the factors that impact LTPA among people with SCI. Based on synthesised evidence, this chapter supports the aims of this research by highlighting a need for HCPs to appreciate the barriers, benefits and facilitators of LTPA if they are to successfully promote a physically active lifestyle. An important finding was that many of the barriers to being physically active were reduced through LTPA participation. Additionally many of the benefits motivated people to continue being physically active. The multiple benefits from being physically active need to be communicated to the SCI community if they are to motivate people to change their exercise behaviour. The synthesis also alludes to an understanding of disability that neither promotes social relational over the medical model (or vice versa). Rather, as seen in the environmental section and restitution section the two models operate simultaneously to frame LTPA and how disability can be understood. The next chapter presents the methodology and methods used to answer the remaining research questions, as set out in the literature review.

Chapter 4: Methodology and Methods

4.0 Overview

In this chapter I describe the methodological approach I take towards answering my research questions (see chapter two). I begin by introducing qualitative research. Next I introduce the underpinning paradigm of interpretivism and the ontological and epistemological assumptions that guide this research. I then go on to describe narrative inquiry as the main methodological approach and introduce my participants and the procedures for data collection and analysis. I further explain the choice of tale to represent the findings, the ethical considerations encountered and possible criteria of which this thesis may be judged against for research quality. At each stage of this chapter I provide a rationale for all of my methodological decisions.

4.1 Qualitative research

There is no clear cut definition of exactly what constitutes qualitative research. Qualitative research means different things to different researchers, but can broadly be described as an umbrella term that comprises many small communities of multiple traditions and multiple methods that involve collecting, describing and interpreting data in an inductive manner (Smith & Caddick, 2012; Smith & Sparkes, 2014). Accordingly, qualitative research may be better understood through some key defining features (Willig, 2013; Smith & Sparkes, 2014). One key feature is the use of qualitative research to explore the lived experience of others and give meaning to these experiences in a social context (Sparkes, 2002). Thus as Smith and Sparkes (2014) explain, qualitative research is a “form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live” (p.14). Qualitative research is therefore not concerned with the quantifiable measuring of facts which preoccupies quantitative research, but aims to understand *what it is like* to experience particular events and conditions (e.g. what it means and how it feels to be physically active with spinal cord injury [SCI]). Another defining feature of qualitative research is the emphasis on textual data which enables participants to share understandings of their worlds in their own words. This can result in the construction of thick, rich descriptions and recording of detailed observations of participants in their natural setting (McNabb, 2004; Creswell, 2013).

Qualitative research was adopted for this project as it was most suited to addressing the overarching aims and answering the research questions. For example, drawing upon the methods of qualitative research (as discussed below) I was able to have detailed

conversations with the physiotherapists in SCI rehabilitation regarding their values and beliefs about physical activity (PA) for their spinal cord injured patients. Furthermore, qualitative research facilitates an understanding of *processes* (Sparkes & Smith, 2014). In this context, qualitative inquiry revealed the process by which physiotherapists attempted to manage hope and expectation of the outcomes of SCI rehabilitation. Another strength of qualitative research in relation to this research project was the ability to immerse myself within the research context for an extended period of time. For example, by attending the activity-based rehabilitation (ABR) centre – Neurokinex – for a period of eighteen months I was able to gain an ‘emic’ perspective (Sparkes & Smith, 2014). Embracing this perspective means getting to know the phenomenon of interest – the participants’ experiences of ABR – as much as possible from an insider’s point of view. Qualitative research therefore additionally provided the means by which to gather detailed, rich accounts of the perceived impact of participating in ABR had on the clients over time.

4.2 An interpretive paradigm

Qualitative research may also be understood by the paradigmatic assumptions that underpin it. A paradigm is set of ideas or beliefs that impact upon the researchers’ way of viewing and interacting with the world (Guba & Lincoln, 1994; McNabb, 2004). Adopting a paradigm provides researchers in a certain discipline with a philosophical framework which determines the nature of reality (ontology) and how reality is known to us (epistemology) (Bryman, 2004; Smith & Sparkes, 2014). Furthermore, the philosophical roots of any method of inquiry challenge the position researchers take as to what should be studied and how the results are best interpreted (McNabb, 2004). This thesis utilised a qualitative methodology underpinned by interpretivism. The interpretive paradigm “is predicated upon the view that a strategy is required that respects the differences between people and the objects of the natural sciences and therefore requires the social scientist to grasp the subjective meaning of social action” (Bryman, 2004, p.13).

The design of each interpretive study was framed by ontological relativism and epistemological constructionism. The underpinning ontological and epistemological assumptions both shape and direct the research process. Ontological relativism, as outlined by Sparkes and Smith (2014) considers “social reality as humanly constructed and shaped in ways that make it fluid and multifaceted. Multiple, subjective realities exist in the form of mental constructions. In this perspective it *is* accepted that physical things exist out there

independent of ourselves” (p.11 emphasis in original). Thus, how people give meaning to objects, or how they interpret the actions of other people, is shaped for example by language and culture and therefore differs between individuals and their environments (Guba & Lincoln, 1994; Sparkes & Smith, 2014). Moreover, ontological relativism fundamentally asserts that there is no singular, external, knowable *truth* because we cannot know reality outside of our subjective interpretations of it. Rather, there are multiple, mind-dependent realities that are socially constructed in this context between participants and the researcher (Sparkes & Smith, 2014).

Additionally, epistemological constructionism positions that researchers are part of what is studied. As Sparkes & Smith (2014) explain, from this perspective:

There can be no separation of the researcher and the researched, and values always mediate and shape what is understood. The knower and the known are interdependent and fused together in such a way that the findings are the creation of a process of interaction between the two (p.13).

Accordingly, approaching this research through an interpretive paradigm enabled me to address the research questions that focus on the subjective experiences of SCI and physical activity (PA) in various contexts.

4.3 Narrative inquiry

Narrative was introduced in the literature review as a methodological approach to explore how individual stories of SCI and LTPA are shaped by both personal and social experiences. Its use in this research is two-fold; 1) it is used to understand how physiotherapists in SCI centres manage hope and expectation of SCI recovery over time in the context of formal inpatient rehabilitation (chapter seven), 2) it is used to understand the clients’ experiences of ABR and the meaning of these experiences on the broader context of their lives and living with SCI (chapter eight and nine). Narrative inquiry and narrative analysis was chosen as the broad underpinning methodology as it offered numerous advantages to this research project. Firstly, in comparison to other types of qualitative analysis, narrative inquiry focuses on one specific genre of discourse; a story. Stories are of importance because they are a key means by which people make sense of their lives following serious injury such as SCI (Smith & Sparkes, 2005; Frank, 2013) (see chapter two). Secondly, there is a strong emphasis in narrative analysis on human lives being culturally and relationally constructed (Smith, *in press*). For example, narrative analysis allowed me to focus on the personal and individual

stories of the clients at Neurokinex whilst also exploring how these stories may have been shaped by narrative resources circulating within and beyond this context (Gubrium & Holstein, 2009).

Thirdly, narrative analysis focuses on both the *whats* (e.g. what is the story about) and the *hows* (e.g. how is the story structured) of talk (Gubrium & Holstein, 2009; Sparkes & Smith, 2014). Other methods of qualitative analysis focus on just one aspect of talk whereas narrative analysis combines the two (Smith, *in press*). As Gibbs (2008) contended, “The analysis of narratives and biography adds a new dimension to qualitative research. It focuses not just on what people said and the things and the events they describe but on how they said it, why they said it and what they felt and experienced” (p. 71). For example, a focus on both the *whats* and *hows* of talk enabled me to examine the physiotherapists’ stories to understand how they managed hope and expectation of SCI rehabilitation and what strategies they drew upon to do this. A fourth advantage of narrative analysis is that it enabled me to explore how the clients at Neurokinex understood their experience of SCI and LTPA in relation to their biographical history; their past, present and projected future. Thus, focusing on stories enables researches to chart the movement of human lives *over time* (Sparkes & Smith, 2014). All this said, there are multiple types of narrative analysis that take different standpoints towards narrative as each serves a certain purpose. To fulfil the above ambitions within this research, I utilised a form of narrative analysis called dialogical narrative analysis (DNA). The rationale and justification for using DNA, as well as the advantages of this type of analysis, are addressed in the latter section on data analysis.

4.4 Sampling and participants

The participants in this thesis include physiotherapists working in SCI centres, clients with acquired SCI and their trainers at the ABR centre Neurokinex. The clients at Neurokinex are referred to as clients and not patients because ABR is a community based LTPA initiative whereby people with SCI can pay to exercise. The clients are paying to exercise with the aid of specialist trainers much like people would pay for a personal trainer at a commercial gym or similar.

4.4.1 Physiotherapists

To explore the experiences of physiotherapists in SCI rehabilitation that inform chapters six and seven, a criterion-based purposive sampling strategy (Sparkes & Smith, 2014) was used to recruit physiotherapists currently working within regional SCI centres in the UK and

Ireland. The inclusion criteria were people who were (a) physiotherapists currently working in a SCI centre (or had left within 6 months of the study), (b) aged 18 and over, and (c) not undergoing treatment for health problems. Initial contact was made with participants through an organisation for professionals in SCI care in the UK and Ireland. Despite differences in healthcare systems, the UK and Ireland share similar management approaches to SCI rehabilitation (Wong et al., 2015). An open letter explaining the rationale for the research project and participant requirements was distributed to all members of the organisation via email from their secretary (Appendix B). The letter ended by asking the respondents, should they be willing to be interviewed, or wish to discuss the project further, to please contact the author on the email or telephone number provided. Recruitment continued until data saturation was achieved (O'Reilly & Parker, 2013). The final sample consisted of 18 participants (13 women and 5 men) from regional SCI centres in the UK and Ireland. The participants were aged between 25 and 56 years' old and ranged in experience in neurological physiotherapy from 2 to 22 years' working in SCI rehabilitation.

4.4.2 Clients and staff at Neurokinex

I first made contact with Neurokinex through the two directors who acted as 'gatekeepers' and facilitated access to the clients and staff in the rehabilitation centre. The sampling procedure utilised to explore the experiences of clients at Neurokinex was purposive sampling and more specifically criterion-based sampling (Patton, 2002; Sparkes & Smith, 2014). This type of sampling is not representative of the larger population but targets people of a clearly defined group who have experienced the same phenomenon. In this case, I was originally concerned with the complete *process* of activity-based rehabilitation (ABR) and sought to recruit clients new to Neurokinex. To reflect this research aim the original criteria for inclusion in the project were as follows: a) clients within one month of starting their ABR programme; b) over the age of 18, and; c) with acquired SCI. However, due to the relocation of Neurokinex to a brand new facility just outside of London (see chapter five for more details), there were very few new clients through the door within the first six months of my research project. Due to the lack of new clients, the original criterion for inclusion was altered to reflect the client base at Neurokinex at that time. Therefore any clients who were over the age of 18 and had acquired their SCI were permitted to take part in the research.

Following approval from Loughborough University Research Ethics committee, initial contact was made with the participants via email from staff at Neurokinex. The staff then discussed my research with their clients during their ABR sessions. If any of the clients

were interested in taking part I then discussed the project with them further and provided them with an introductory participant information sheet (Appendix C). In total, 10 clients took part in the study (Table 4.1). The clients varied in terms of their age, time since injury, level of injury including both complete and incomplete SCI, time at ABR and cause of SCI (e.g. fall from height, road traffic accident, violence). At the start of my time at Neurokinex there were 5 trainers working full time at the facility. All 5 trainers and one of the directors also agreed to take part in the study to enable me to gain their view and experiences of ABR. The trainers were all aged between 25 and 30 years' old and had 2 to 7 years' experience working in ABR. They were all from a sport science background including sports therapy and personal training. One of the trainers originally worked in an ABR centre in North America and came to the UK to help run Neurokinex.

Table 4.1: Clients at Neurokinex

No.	Age*	Time post SCI*	Time at ABR*	Level of SCI
1	26	2.5 years	3 months	T6-T8 complete
2	52	25 years	2 months	T6 incomplete
3	37	4 years	1 month	T5 complete
4	44	28 years	1.5 years	C4-C5 incomplete
5	47	3 years	1.5 years	C4-C5 complete
6	50	4 years	2.5 years	T5-T6 complete
7	20	1 year	2 months	C3-C4 incomplete
8	22	11 months	2 months	T6 complete
9	36	20 years	6 months	T6 incomplete
10	29	2 years	1.5 years	T12 complete

4.5 Data collection

Data collection for this research spanned a period of 18 months from April 2013 to October 2014. For the physiotherapy study I spent three months travelling across the UK and Ireland to interview physiotherapists from different SCI centres. For the study at Neurokinex, I used a combination of interview and observation methods and attended the centre every other week for the whole 18 month period. In addition I completed a reflexive journal throughout the research process that enabled me to document the way in which my position in the field impacted upon the research process.

4.5.1 Interviews

A qualitative interview can be defined as having a conversation with purpose whereby the researcher seeks to gain insight into the participant's perceived experiences, feelings and perceptions. As Sparkes and Smith (2014) elaborate:

An interview can be usefully described as a craft and social activity where two or more persons actively engage in embodied talk, jointly constructing knowledge about themselves and the social world as they interact with each other over time, through a range of senses, and in a certain context (p.83).

There are various broad types of interviews to suit the different demands of a research project; structured, semi-structured, unstructured or group interviews. A semi-structured interview was used due to the flexibility of this approach to data collection where the researcher can alter the sequence of questions or probe for more information where necessary (Gratton & Jones, 2004). The use of semi-structured interviewing therefore allows for a pre-planned interview guide to direct the discussion, while giving the participants a degree of flexibility in expressing their opinions through open ended questions (Brinkmann, 2013). Prior to commencing the interviews, I provided all participants with information about the study and gained informed consent (Appendices D-G). During this process each participant was informed of their right to withdraw from the project, their freedom not to answer any questions and that they could terminate the interview at any stage without having to give reason. To aid confidentiality and anonymity, it was made clear that all identifiable information would be removed and pseudonyms would be used in any future publication.

All of the physiotherapists were involved in a semi-structured interview that lasted between 60 and 150 minutes. The interview questions explored a wide range of subjects, including the role of physiotherapy within SCI rehabilitation, PA within in-patient rehabilitation and PA in the community for this population. Furthermore the questions probed for insights into how the physiotherapists' managed hope and expectations with SCI rehabilitation (Appendix H). Physiotherapists were also given the opportunity to raise any issues regarding SCI rehabilitation and PA that were not included in the interview guide. In addition, field notes and initial thoughts were written in the form of a reflexive journal after each interview. This process allowed any initial concepts raised in previous interviews to be explored in more detail with the subsequent participants. All interviews took place at a

location of the participant's choosing and were digitally recorded and transcribed verbatim using the speech recognition software Dragon (Dragon Natural Speaking 11.5).

I first conducted semi-structured life-history interviews with the 10 clients at Neurokinex to explore their lifestyle before SCI, life with SCI, the role of PA and their experiences ABR (Appendix I). After the clients had shown initial interest in taking part in my research project I further discussed the details of the project face-to-face at Neurokinex, and if they were willing to participate, arranged the first interview. All interviews took place at a location of the participant's choosing (e.g., Neurokinex, home). By interviewing each client over time I was able to collect detailed stories about how they had lived their lives and their specific experiences with SCI. The clients were interviewed a second time, approximately one year later. In this interview I asked the clients to elaborate on their experiences of ABR over the last year. I also took this opportunity to seek clarification/elaboration of any responses from the first interview (Appendix J). The total duration of the interviews lasted between 60 and 200 minutes and were transcribed verbatim using Dragon as soon as possible after each one. The use of interviews also enabled the five rehabilitation staff to share their experiences of developing ABR programmes for people with SCI (Appendix K). Rehabilitation staff, referred to as trainers, were interviewed once. These interviews lasted between 45 and 120 minutes, and were transcribed verbatim using Dragon software.

4.5.2 Participant observation

To complement the storied experiences constructed through interviews, I additionally collected observational data at Neurokinex. Participant observation is one method that enables the researcher to reconceptualise the difference between what is *said* in interviews, and what is *done* in practice. Furthermore, observational methods enable the examination of peoples' lives in *real time* and "record the mundane, taken-for-granted, and unremarkable (to participants) features of everyday life that interviewees might not feel were worth commenting on" (Sparkes & Smith, 2014, p. 100). As Gubruim and Holstein (2009) contend, social reality explored through narrative inquiry does not need to stay within the boundaries of conversation:

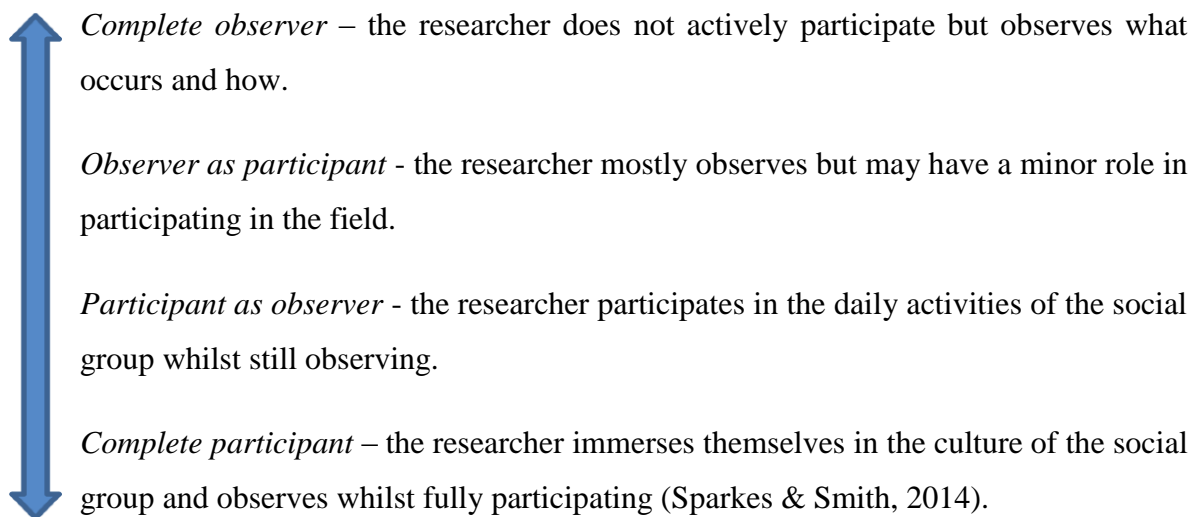
The reality in view is about *both* the substance of stories and the activity of storytelling, it is imperative that in addition to what is said and recorded on any

occasion, researchers go out into the world, observe and listen, and document narrative's everyday practices (p.15).

Observational methods as data collection involve perceiving the workings of people, culture and society through one's senses and documenting these in field notes. Therefore, observational methods provide a contextual understanding of the experiences of ABR at Neurokinex whilst they are occurring. Furthermore, it involves the researcher spending time learning about people in a specific surrounding (O'Reilly, 2012). Additionally O'Reilly (2012) proposes that:

It is only by being in context, being there to talk with and listen to the people you are researching as they experience things and as they go about their daily lives, that you can get them to tell you about how they feel and think (p.14).

The difference with participant observation is that the researcher *participates* (physically, cognitively, socially, sensually and/or emotionally) in varying degrees in the lives and culture of the participants (Sparkes & Smith, 2014). It is, however, difficult to distinguish between observation and participant observation as the researcher can take on a range of roles within the field. These include:



These different roles are not static but exist along a continuum as the researcher may move between positions during data collection. In addition, to account for the different roles researchers can adopt in the field, they must be reflexive about how they have influenced the data collected in their notes (Wolcott, 2005). Within observational settings field notes

include, but are not limited to; what is going on, commenting on the people in the field, where and when the social interactions take place and why this is happening (O'Reilly, 2012; Sparkes & Smith, 2014). My role within the group shifted between complete observer and participant as I tried to fully immerse myself within the research environment at Neurokinex. I aimed to participate as fully as possible by acting as an assistant to the trainers. This role involved fetching equipment, helping to transfer clients from their wheelchair to the plinth or the floor, and supporting the clients' bodies as they exercised. Shortly following a period of observation (either during a break at the centre, or as soon as I was home), observations and thoughts were recorded in detailed field notes. Also observed and documented were the interactions that took place on the gym floor or in the waiting area, the ways in which the trainers, clients and their family members interacted and spoke to each other, and the stories told in conversations throughout the day. I wrote in a reflexive journal after every visit to Neurokinex to record my initial thoughts and impressions of the data I was collecting as well as how my presence in the centre was influencing the interactions taking place. An example of my reflexive thoughts on my observational roles at Neurokinex is discussed in the next section.

4.5.3 Reflexive journal

At the start of the research process I began a reflexive journal about all things concerned with my studies. In general terms, to be reflexive involves "focusing close attention upon one's own actions, thoughts, feelings, values, identity, and their effect upon others, situations, and professional and social structures" (Bolton, 2005, p.10). It is imperative within qualitative research to be reflexive through a deeper questioning of how and what is being studied (Creswell, 2013; O'Reilly, 2012). As Silverman (2011) explains, reflexivity in research is "The self-aware analysis of the dynamics between researcher and participants, the critical capacity to make explicit the position assumed by the observer in the field, and the way in which the researcher's positioning impacts on the research process" (p.22). Moreover, to be reflexive about research shows that informed, strategic and principled methodological decisions have been made, along with fair and balanced interpretations of the data (Sparkes & Smith, 2014).

As a researcher delving into observational methods of exploration I needed to be aware of the myriad of limitations and advantages that are associated with studying other human beings (O'Reilly, 2012). Furthermore I needed to confront any prejudices about Neurokinex and any preconceptions about the ABR process that I was studying. The reason

for this is that it is only once preconceived ideas about what is being researched are realised that the researcher can be open to surprises in the field (O'Reilly, 2012). According to Wolcott (2005) such reflexivity in research involves *disciplined subjectivity* through an attention to bias in research. Moreover, bias is unavoidable and necessary as in the total absence of bias the researcher would not even be able to start a research project. Therefore through this project I tried to identify my own preconceptions about Neurokinex. To do this, Wolcott (2005) recommends, “covet your biases, display them openly and ponder how they can help you formulate both the purposes of your investigation and how you can proceed with your inquiries. With biases firmly in place, you won't have to pretend to complete objectivity, either” (p.157).

I had heard many stories about Neurokinex before I first visited the new centre in Watford. The directors of Neurokinex had used their 'sales pitch' on me to convince me of the benefits of their set-up. On the other hand, through my experience working as a sports massage practitioner at the London 2012 Olympic and Paralympic Games, I had encountered neurological physiotherapists who were sceptical of the benefits alternative therapies such as ABR could bring to people with SCI. I was therefore aware of the perceived benefits and drawbacks of ABR from different stakeholders within SCI rehabilitation. Being reflexive in the field required me to constantly question the way in which observations were reached and interpreted (Silverman, 2011). One of the considerations that I had increasingly been forced to acknowledge was my role between observer and participant as mentioned earlier. Below is a piece from my reflexive diary about how I negotiated these roles as I moved around Neurokinex with clients and their trainers. Further extracts of my reflexive diary are provided throughout my empirical results chapters as discussed below.

Extract of reflexive diary - 6th August 2013

It was really busy in the centre today. At one point there were 5 clients with 5 members of staff which made me the only assistant. I didn't mind helping at all, in fact it made me feel trusted and that the staff are more comfortable having me around. By helping out with fetching equipment, throwing a ball during an exercise or assisting with walking, I feel a part of the centre rather than an outsider. Maybe I have moved into the role of participant as observer during these times. I wonder if this is changing the clients' view of who I am in the centre? I am aware that I rarely just observe without any interaction. Wherever I am, whether that be sitting in the waiting area or on the gym floor, people always talk to me. Therefore I try and observe what is going on away from the interaction that I'm involved in. I think this is the only way I can adopt this role. On the other hand the role of complete participant is probably not possible to embrace as I will never be able to fully participate as a trainer or client.

4.6 Data analysis

To make sense of the data for the physiotherapy study, two separate methods of analysis were utilised. Although this research is broadly informed by narrative inquiry, a thematic analysis was chosen as the most suitable method to analyse the data on physiotherapists and PA in chapter six. This method is still underpinned by interpretivism and framed by ontological relativism and epistemological constructionism. However, the rationale for using thematic analysis was that I was able to include data that was not just restricted to the stories told about PA. As Frank (2010) explains, a story at the very least contains a complicating action (some form of obstacle or dilemma) and some form of resolution (response to the complicating action). Much of the data on PA was presented more as an account rather than as a story. Therefore to include as much data as possible, and have a fuller understanding of the physiotherapists' thoughts and experience with PA, a thematic analysis was used. The analytical perspective used to make sense of the storied data in chapters seven to nine, was DNA.

4.6.1 Thematic analysis

A six stage inductive thematic analysis as outlined by Braun and Clarke (2006) was conducted on the interview transcripts. This method was used to identify main patterns in the data without restriction to a pre-existing coding scheme. In the first phase I transcribed all of the interviews and became immersed within the transcripts by reading them through multiple times and making initial notes on ideas and patterns within the data. The second phase involved generating initial codes from the data which identified key features or points of interest within the transcript. See figure 4.1 for an example of a coded section of data. Once

all data was coded, the third phase of the thematic analysis was to extract all of the codes and collapse them into potential themes. This stage re-focused the analysis to the broader level of themes and involved combining codes to form overarching patterns within the data. At this stage I identified a collection of candidate themes and sub-themes within the data. A candidate thematic map of this early stage of analysis is shown in figure 4.2.

The fourth phase involved refinement of these themes as I reviewed the entire data set to check if the themes were plausible and formed a coherent and consistent pattern. As Braun and Clarke (2006) explain, this stage is vital to check whether the initial thematic map ‘accurately’ reflects the meanings in the whole data set. It was during this phase that the sub-themes were collapsed leaving the three main overarching themes. Sub-themes can be useful for structuring large and complex themes. However, this decision was made as there was not a clear and identifiable distinction between each of the sub-themes when checked against the entire data set (Braun & Clarke, 2006).

Data extract	Coded for
<p>The problem is physios are <u>not trained to properly fitness train a patient</u>. A <u>sports therapist may have learnt to get someone fit</u>, but I believe in spinal cord injury there are <u>not many physios who can just take a patient to the gym and give them fitness training</u> that would work for them.</p>	<ul style="list-style-type: none"> - lack of training - other health professionals have PA expertise - physio lacks skills to prescribe exercise programme
<p>I think we as physios, we are <u>best placed to be the ones to educate and advise and encourage our patients to take part in physical activity</u>... There's <u>literature</u> out there to support that <u>the messages and education we give spinal cord injured patients in their first few weeks of rehab</u> tend to stick with them...</p>	<ul style="list-style-type: none"> - physios best placed to promote PA - aware of research on PA and SCI - importance of PA messages in early rehabilitation
<p>I guess the <u>dangers</u> to me are that you are <u>misinforming patients of unrealistic expectations</u> and you could be <u>setting them up for a crash</u>. You know <u>they've already had a life changing traumatic event</u>, you <u>don't want them to build all their hopes, all their expectations... on a potential false hope</u>.</p>	<ul style="list-style-type: none"> - dangers of ABR - misinforming patients - unrealistic expectations - potential impact on PWB - potential for false hope

Figure 4.1: Example data extract with codes

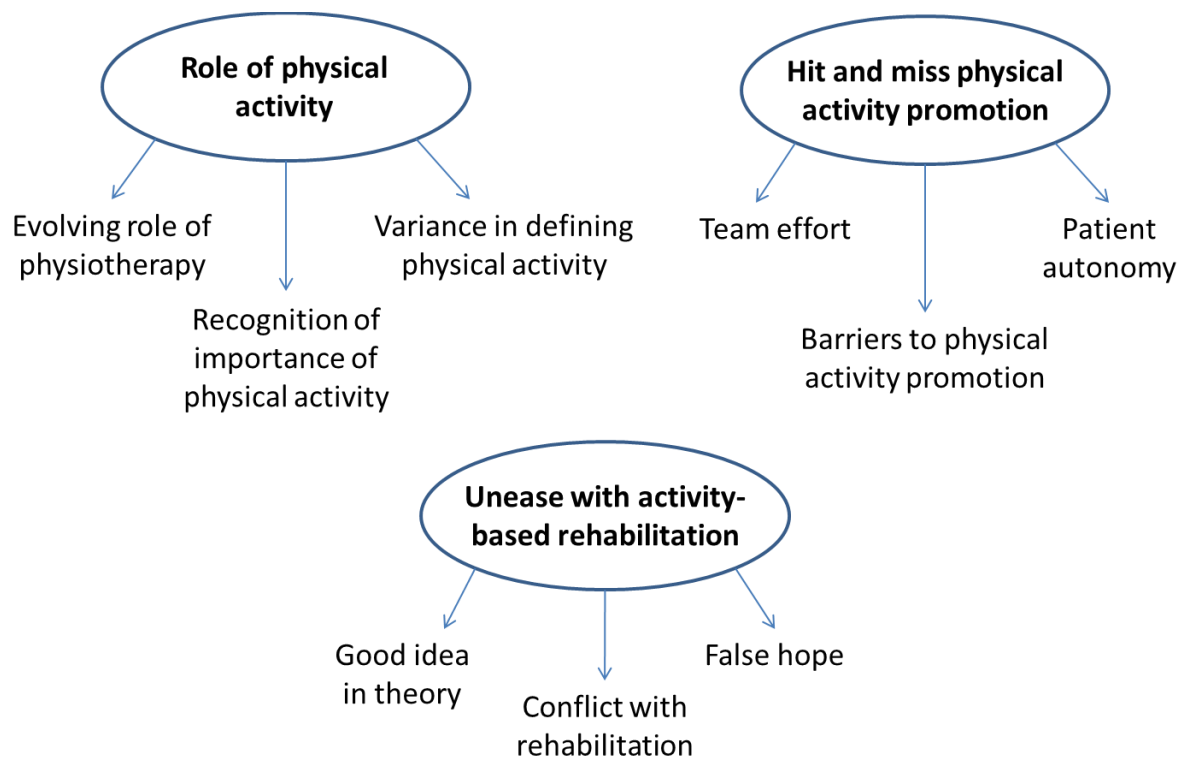


Figure 4.2: Initial candidate thematic map

During the fifth phase the final refinements were made. This involved defining and refining the themes to identify the essence of each theme, and how they fitted into an overall story in relation to the purpose of the research. At this point, the names of the final themes were altered to more accurately reflect the story each theme was telling regarding the physiotherapists’ perceptions about PA and what they did in relation to promoting PA. These final names were considered to be more succinct and immediately provide the reader with a sense of the crux of each theme (Braun & Clarke, 2006). Figure 4.3 illustrates the refinement process with an accompanying narrative of each theme.

The sixth and final phase involved writing up the report. As Braun and Clarke (2006) explain, it is vital the final analysis “provides a concise, coherent, logical, non-repetitive, and interesting account of the story the data tell – within and across themes” (p.93). With this in mind, the results chapter (six) includes sufficient evidence of each theme through the use of concise data extracts. Furthermore, the write-up of this research goes beyond description of the data to interpret the data in light of current research in PA and health promotion.

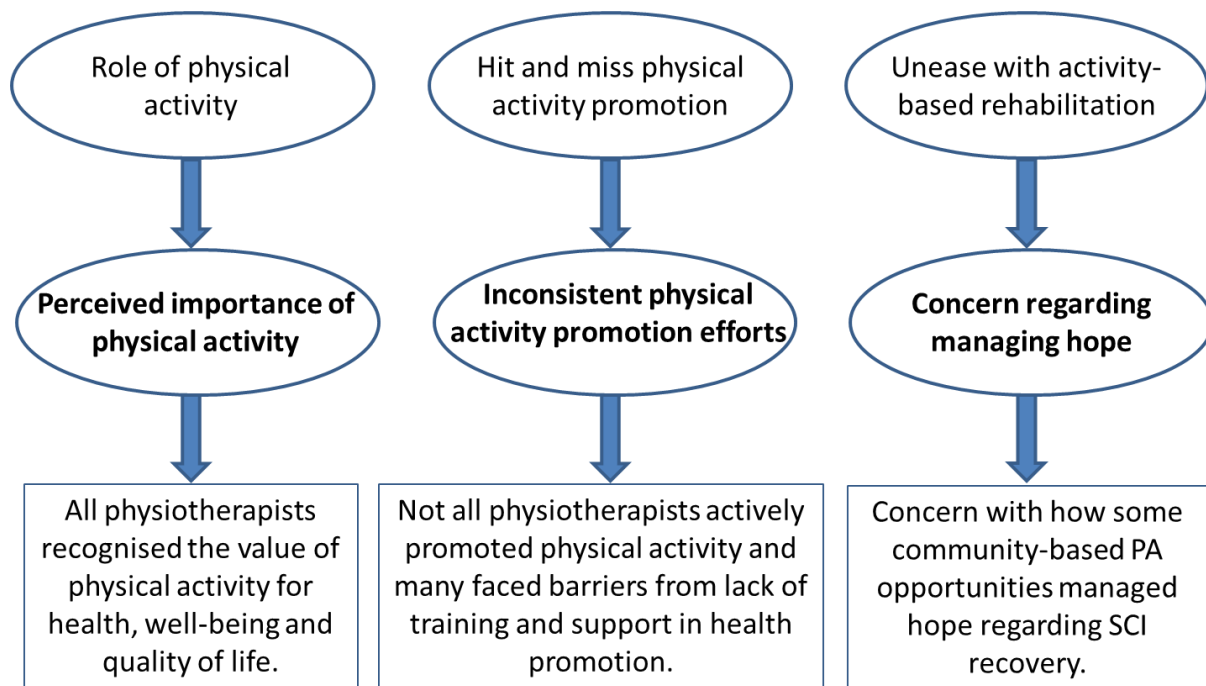


Figure 4.3: Refining final themes with accompanying narrative

4.6.2 Dialogical narrative analysis

Dialogical narrative analysis (DNA) was the analytical perspective used to make sense of the data for the empirical results chapters seven to nine. A DNA is concerned with not only the story told by participants, but also the *work* that stories *do* for and to people. As Frank (2010) contends, DNA “studies the mirroring between what is told in the story – the story’s content – and what happens as a result of telling that story – its effects” (pp.71-72). Thus, the principle analytical concern with DNA is the appreciation of stories as actors in people’s lives (Frank, 2010, 2012). Therefore, through DNA, stories are examined for what is said, the narrative resources used to help structure storytelling, what stories do and the reasons why a person chooses to represent their life using a particular story (Smith, *in press*).

The method for carrying out a narrative analysis purposely lacks a prescribed set of steps that should be followed meticulously (Sparkes & Smith, 2014). Indeed, Frank (2010) describes DNA as “movement of thought” that asks questions of the data in analysis as “some methods are more useful for the questions they offer than any procedures they prescribe” (pp.72-73). Therefore the method of DNA should be understood as a heuristic guide rather than a set of procedural and prescriptive guidelines. Drawing upon this approach to analysis encourages movement of thought, as for Frank, “Analytic or interpretive thought that is moving is more likely to allow and recognise movement in the thought being interpreted”

(2010, p.73). Moreover, as Smith (*in press*) illuminates, “Movement of thought can take the analyst in unexpected and fertile directions, breathing fresh life into moribund concepts, encouraging theoretical curiosity, and provoking new ways of seeing in the process” (p.12). Thus, adopting DNA as a heuristic guide and method of questioning can spur imagination and inspiration that in turn can lead to new insights and understanding of SCI and PA.

Making sense of the data through DNA involved various analytical stages. It was an iterative and cyclic process that began alongside data collection and continued throughout the writing up stage. The process began during data collection and transcription. As Smith (*in press*) notes, transcription is much more than a technical exercise, it is part of the analytic process. I took notes of the stories that appeared to be emerging throughout data collection and transcription. This was the start of the period of indwelling. Indwelling further involved immersing myself in the data by reading and re-reading interview transcripts and field notes and attempting to understand the participants point of view from an empathetic position (Maykut & Morehouse, 1994). The next stage involved (loosely) coding the data in the interview transcripts and field notes with conceptual comments. To identify the types of stories being told and narrative themes and thematic relationships in the data, it was important not to over-code and break the stories apart. Indeed, as Smith (*in press*) explains, the purpose of a narrative analysis is to “keep the story intact in order to preserve and examine the wealth of storied detail contained in it” (p.8). That said, identifying stories in the data first involved deciding what is a story. As illuminated in the above section on thematic analysis, not all textual data is a story. Stories are a tale people tell, where “one thing happens in consequence of another” (Frank, 2010, p.25). Moreover, stories also include characters, a complicating action or point of view, and a plot. However, they are very rarely articulated as “fully formed” narratives (Frank, 2010). Therefore, operating with this working understanding of stories I tried to identify both individual stories (e.g. participants’ stories developed in the interview transcript) and the larger narratives operating within the environment and culture in SCI centres and at Neurokinex that were noted during observation.

To start the analytical process, Smith (*in press*) suggests the following strategies for getting to grips with stories identified in the data. Firstly this involved focusing on the content of the story to identifying narrative themes and thematic relationships. This focus addresses the *whats* of talk to answer questions such as “What are the common themes or threads in the story?” Secondly this involved identifying the structure of the story to focus on *how* the story

is put together and identify the types of narrative resources drawn upon in each story. To further address the *effects* that these stories had on the participants, they were considered in light of a set of dialogical questions. Drawing upon Frank (2010, 2012) and Smith (*in press*), examples of the dialogical questions used include: *resource questions* (What narrative resources do the participants draw upon to shape their subjective experiences of SCI and PA?); *circulation/affiliation questions* (Who do the participants' stories connect them to?); *identity questions*: (How do participants tell stories to explore whom they might become?); *function questions* (As "actors", how do the participants' stories shape their actions?); and *interpretation questions* (What details may have been expected but were omitted?).

To explore these questions I drew upon writing as a form of analysis (Richardson, 2000). As Sparkes and Smith (2014) explain, writing is not a mopping up activity to be competed at the end of a research project. Rather, analysis happens in the process of writing because in doing so one can progressively discover ideas and recognise the actions of stories. Moreover, according to Frank (2012):

The analysis of the selected stories takes place in attempts to write. The research report is not post hoc to an analysis that is completed before writing. Rather, reports emerge in multiple drafts that progressively discover what is to be included and how those stories hang together. In DNA, stories are first-order presentations of life, and writing about stories is a second-order act of narrative representation (p.43).

My analysis of the stories told by the physiotherapists regarding their management of hope and expectation in SCI rehabilitation, and the stories told by the clients and trainers at Neurokinex about their experiences of ABR, evolved gradually and progressively. Thus, writing was a process of representing these stories with theory and revising these stories and theories as required (Smith, *in press*). However, it is important to note that these final accounts do not 'finalise' the participants' lives by offering the last word on who or what they may become (Frank, 2012). As Sparkes and Smith (2014) contend, "this means respecting in analysis that stories always, like human lives that are spun through them, have the capacity to change and that as long as they are alive, bodies telling stories have not yet spoken their last word" (p.132). The use of DNA also allowed me to build a typology of stories concerning ABR as I was able to identify *types* of narrative that people were drawing upon to construct their experiences. For Frank, building a typology does risk "putting stories into boxes, thus allowing and even encouraging the monological stance that the boxes are more real than the

stories, and the types are all that need to be known about the stories” (p.119). On other hand, a typology construction:

Allows recognising the uniqueness of each individual *story*, while at the same time understanding how individuals do not make up stories by themselves... A typology of *narratives* recognises that experience follows from the availability of narrative resources, and people’s immense creativity is in using these resources to fabricate their stories (p.119, emphasis in original).

Building a narrative typology in chapter nine allowed me to identify the different underlying plots of stories of ABR, the consequence of telling these stories, and how hopes and expectations were managed in this context. The observational and reflective data recorded from my immersion at Neurokinex served to complement the data collected during interviews with participants. In particular, the typologies in chapter nine were conceptualised through *both* the substance of the stories told by participants, and the activity of storytelling I observed in the everyday practices and interactions at the centre (Gubruim & Holstein, 2009). For example, two of the narrative types were clearly identifiable in the participant’s stories of their hope and expectations of ABR. The third narrative type was only conceptualised after returning to Frank’s (2010, 2012) dialogical questions concerning interpretation and further analysis of the data in my field notes and reflections. This is not to say that the observational data conflicted with the data collecting during interviews. Rather, the field notes served to identify a narrative thread through observation that was silenced from the everyday conversations in interview (see critical reflections: Box 9.2 in chapter nine and methodological implications in chapter ten).

4.7 Representation

The four empirical results chapters (six to nine) outline what was found in this thesis in relation to the research questions. These results chapters are presented in chronological order starting with formal SCI rehabilitation that occurs within a SCI centre before turning attention to PA upon discharge from this context into the community. Therefore chapters six and seven, which address physiotherapists’ beliefs and values regarding PA in SCI rehabilitation and how they manage hope and expectation in this context, are presented first. Then the experiences of ABR for people with SCI and the trainers at Neurokinex are presented in chapters eight and nine.

All empirical chapters are written in the style of a ‘disrupted realist tale’. A traditional realist tale is the dominant means of representing qualitative findings and is characterised by *experiential author(ity)* (researcher/author absent from finished text); the *participant’s point of view*; and *interpretive omnipotence* (theoretical account of the story) (Sparkes & Smith, 2014). Together, these characteristics operate to faithfully represent the participants’ point of view whilst drawing upon theories and concepts to explain the findings. As Sparkes (2002) explains:

The realist conventions connect theory to data in a way that creates spaces for participants’ voices to be heard in a coherence text, and with specific points in mind. When well constructed, data-rich realist tales can provide compelling, detailed, and complex depictions of a social world. (p.55)

A realist tale is written in traditional academic prose and framed by the voice of a disembodied author (Sparkes & Smith, 2014). However, as Sparkes (2002) suggested, the traditional realist tale can be modified to bring to light the author’s role in the construction of the text. With this in mind, I present my interpretive role in the research process and construction of findings by including a series of critical reflections – taken from my reflexive journal – throughout the empirical chapters. These critical reflections are extracts from my reflexive journal that illuminate my analytical thinking at various stages in the research project. Thus, my realistic tale is *disrupted* as I position myself as a reflexive qualitative researcher throughout the empirical chapters.

The empirical chapters seven to nine that were analysed through a narrative lens, additionally drew upon the standpoint of a *story analyst*. As Smith and Sparkes (2008) contend, there is a difference between a story analyst and a story teller. On the one hand, story analysts conduct an analysis of the narrative whereby “the researcher steps outside or back from the story and employs analytical procedures, strategies and techniques in order to abstractly scrutinise, explain and think about its certain features” (p.21). On the other hand storytellers “move away from abstract theorising and explaining toward the goals of evocation, intimate involvement, engagement and embodied participation with stories” (p.21). Storytellers therefore present their research through creative analytic practices such as autoethnography, ethnodrama and fiction. As a story analyst however, I was concerned with the context of the story, the where’s (place), the when’s (time), whilst addressing additional

questions of what (in relation to content) and how (the story is told in a certain way) (Gubrium & Holstein, 2009).

To address the *whats* and *hows* of storytelling, Gubrium & Holstein (2009) suggest using a technique called *analytical bracketing*. When conducting a DNA, analytical bracketing first involves bracketing the storytelling scene to bring the *content* of the story into focus (Frank, 2010). Exploring the content of the story allows questions to be answered regarding *what* is being said in the story, whilst temporarily putting aside empirical matters such as *how* the stories were told and *how* the stories were structured (Gubrium & Holstein, 2009). The next stage of a DNA brackets the content of the story and brings the storytelling back into the analysis as the *hows* of talk are examined alongside the *work* that these stories *do* to and for people (Frank, 2010; Smith & Sparkes, 2014). Chapter seven is presented as a complete dialogical narrative analysis as the questions of *how* physiotherapists manage hope and expectations and *what* strategies they draw upon are examined. Chapters eight and nine turn attention to the experiences of ABR by participants with SCI and their trainers at Neurokinex. Through this process of analytical bracketing, chapter eight focuses upon the content of the stories to answer the *what* questions (e.g. What were the barriers to exercise? What did people do to overcome these barriers? What facilitated continued engagement with ABR?). Chapter nine examines the *hows* of talk and identifies the types of narratives that were drawn upon to scaffold and structure the stories of ABR. Together these two chapters address the stories told by participants and the effects of telling these stories.

4.8 Ethical considerations

Ethical conduct throughout this research included both *procedural ethics* and *ethics in practice* (Guillemin & Gillam, 2004; Sparkes & Smith, 2014). Procedural ethics refers to formally obtaining approval from the university ethics committee. Whereas ethics in practice is considered as a *process* that requires on-going maintenance and reflection throughout the study (Guillemin & Gillam, 2004; Sparkes & Smith, 2014). The difference between these two ethical standpoints is important as it emphasises that ethical considerations in qualitative research are not something to be ticked off once clearance is granted by the ethics committee. Rather, ethical considerations should remain at the forefront of the researcher's mind as they face numerous ethical dilemmas over the course of a study.

The ethical considerations of this study were addressed in the following manner. Firstly, as a form of procedural ethics, ethical approval was granted by the Loughborough

University Research Ethics Committee. As part of my application for ethical approval, I outlined the potential risks to the participants due to the sensitive nature of the research topic (i.e. trauma and SCI). I acknowledged there was the potential need to manage any distress arising from the participants' involvement in the research. In practice, to help prevent and manage distress arising from participating in interviews and my observations at Neurokinex, several precautionary steps were undertaken. For example, I allowed the participants to divulge as much information as they were comfortable sharing during interviews. I did not ask them to discuss any traumatic experiences of SCI or specifically ask questions that might cause discomfort or distress. In this instance questions regarding problematic terms such as *acceptance* of SCI or *recovery* were avoided unless the participants broached the subject themselves (see chapters seven and nine for further discussions of these terms). Should the participant feel uncomfortable about any issues that I raised, they were free to change the topic without giving any reason. They were told and reminded that at any time they could command the digital tape recording to be stopped or indeed terminate the interview. Participants were also provided with a number of professional support and information networks in case they experienced any discomfort during or after the interview (Appendix L).

Secondly, I adopted the principles of *relational* and *reflexive* ethics to help ensure that the broad procedural ethics considered at the beginning of the research continued informing any issues that emerged as ethics in practice (Guillemin & Gillam, 2004). This involved early consideration of the ethical issues that might arise, as well as scrutinising the actions of the researcher and participants during the research process. Furthermore reflexivity as ethics includes respecting the dignity and autonomy of the participants and negotiating the researcher's desire to gain rich descriptions, whilst caring for the participants' well-being. Moreover, reflexive ethics does not prescribe a specific course of action for any ethical dilemmas, but rather encourages sensitising oneself to these moments and adapting responses in ethical and moral ways (Guillemin & Gillam, 2004; Lahman et al., 2011). The critical reflections throughout each empirical results chapter provide some examples of reflexive and relational ethics in practice. I was mindful throughout my data collection of the researcher-participant relationships I was building with the physiotherapists and the clients and trainers at Neurokinex. I tried to take on the role of active listener to help each participant tell their stories in their own time and in their own words (Sparkes & Smith, 2014). To achieve this I tried to gain a good rapport with all participants and was attentive to what the participants were saying whilst upholding a non-judgemental perspective. On the other hand I was aware

not to become too emotionally involved or attached to the participants. Building friendships with participants could impact upon my role as researcher and restrict the stories participants might tell me as a friend. I was also aware of the potential therapeutic benefit to participants of discussing traumatic experiences and therefore it was necessary that I highlighted my role as a researcher and not as a counsellor (Willig, 2013).

Thirdly, there was a need throughout this thesis to manage what Kaiser (2009) refers to as *deductive disclosure*. That is, although pseudonyms were used to aid confidentiality as outlined in the informed consent, there is the potential for other individuals at Neurokinex (e.g. clients, family, friends, trainers, carers) to be able to identify the clients who participated in this study. Hence I had to negotiate between providing rich descriptions of participants' experiences whilst avoiding the possibility of their comments being traced back to the individual. Thus, I have removed the pseudonyms from the client demographics in table X, and chose not to include the level and time of injury following each quote from the clients. On the other hand, the directors gave permission for Neurokinex to be used in research reports and therefore a pseudonym was not necessary. In addition all participants gave permission for the rehabilitation centre Neurokinex to be identified in this thesis. This allowed me to present a more detailed description of Neurokinex as provided in chapter five. Similarly with the physiotherapist in chapters six and seven, any identifying information that would reveal their position/rank, or could identify the SCI centre was removed to uphold confidentiality and anonymity.

4.9 Criteria for judging qualitative research

In recent years there has been much debate in the literature revolving around the various claims as to what counts as 'good quality' qualitative research (Richardson, 2000; Sparkes & Smith, 2009; Tracy, 2010). Qualitative research methods are underpinned by different philosophical positions and epistemological assumptions. Therefore the intents and purposes of an autoethnography for example, do not match those of a poetic representation or a realist tale. Lincoln and Guba's (1985) criteria for judging the trustworthiness of qualitative inquiry (i.e. credibility, transferability, dependability and confirmability) was proposed to be a universal marker of good quality research. However, Guba and Lincoln (1989) themselves acknowledged that their original concept of trustworthiness was parallel to the criteria of validity, reliability, objectivity and generalisability for judging quantitative research. This parallel perspective is not suitable for judging qualitative inquiry as it is philosophically

contradictory. It assumes that these four criteria will distinguish between trustworthy and untrustworthy interpretations of reality and therefore getting at the 'true' version of reality (Sparkes & Smith, 2009).

Sparkes (1998) proposed that alternative criteria should be used to judge qualitative inquiry through the letting go perspective. This by no means suggests that anything goes in qualitative research. Rather, the term validity should be abandoned and judgements should be made based upon lists of criteria that are appropriate to the form of inquiry (Sparkes & Smith, 2009). These criteria are not universal or static in nature, but are lists of characterising traits that can change over time and in different contexts (Sparkes & Smith, 2009). For example, Lieblich et al., (1998) suggested that narrative inquiry might be judged based on criteria such as width, coherence, insightfulness and parsimony. Richardson (2000) further proposed that a good piece of qualitative research should provide a substantial contribution to social life, have aesthetic merit, be reflexive, provide impact, and portray an expression of reality. As this study was guided by a relativist approach, the criteria for judging the quality of research were drawn from an ongoing list of characterising traits as described below (Smith & Deemer, 2000; Sparkes & Smith, 2009; Tracy, 2010; Sparkes & Smith, 2014; Morse, 2015). These criteria guided my thoughts and actions to ensure the quality of my work and may be drawn by others to make their own judgements about the quality of this thesis.

For example, the worthiness of the topic was illustrated in the rationale for the project by highlighting health promotion in SCI populations as a relevant, timely and significant issue. Rich rigor was ensured by developing a sample appropriate for the purpose of the study and generating data that could provide meaningful and significant claims. Moreover, the significant contribution of this work advances knowledge of SCI and PA empirically, methodologically and practically. Coherence of the research was demonstrated by how well the study hangs together in terms of the purpose, methods, and results. To demonstrate reflexivity and further enhance quality, this study also used an audit trail to document detailed descriptions of the research process and decision making process. My supervisors acted as 'critical friends' and independently scrutinised the audit trail in terms of both data collection and theoretical matters (Sparkes & Smith, 2014).

Furthermore participants were also contacted after their interview to offer any subsequent feedback on the interview process and reflections on the initial interpretations of the data. Only a couple of participants took the opportunity to share their views. These were

the physiotherapists from the SCI centres. They reported naturalistic generalisability in that the data resonated with their experiences of SCI rehabilitation as they were able to make connections with all three themes. As Stake (1995) explains, naturalistic generalisations are “conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves” (p.85). This process is not to be mistaken with member checking which seeks to find the data credible by matching the participants and researchers interpretations of the data (Lincoln and Guba, 1989; Morse, 2015). Rather, the fact that the participants were able to connect with the themes and recognise themselves and their colleagues in the data illustrate naturalistic generalisability (Delmar, 2010).

4.10 Summary

In this chapter I have described my approach to conducting this PhD research project from process to product. I have outlined the type of research used alongside the underpinning philosophical assumptions, and the procedures I followed to collect, analyse and present my research findings. I further described the ethical standards that guided my conduct and suggested some criteria by which readers may assess the quality of my work. In the next chapter a contextual background to Neurokinex and an overview of the current thinking regarding ABR is offered.

Chapter 5: Setting the Scene at Neurokinex

5.0 Overview

The aim of this chapter is to contextualise the thesis by providing an introduction to Neurokinex. The first section provides a brief historical overview of the organisation and how Neurokinex evolved from the Standing Start Trust. The second section explains the premise behind activity-based rehabilitation (ABR) as a form of leisure time physical activity (LTPA).

5.1 From Standing Start to Neurokinex

Neurokinex is an ABR centre based just outside North London that offers intensive individualised exercise programmes for people with spinal cord injury (SCI). It is a community-based LTPA initiative where people with SCI can pay to exercise with the aid of specialist health practitioners within an adapted gym facility. Neurokinex is a re-brand of the original ABR centre Standing Start. The founder of Standing Start opened the first ABR centre in Cambridge in the UK in December 2008 after a promising visit to Project Walk in California⁴. Underpinned by the five phases of recovery, Project Walk claims that recovery from paralysis following SCI is possible (see *www.projectwalk.com*). Despite the best efforts from the team at Standing Start, the fact that the centre was based on Project Walk – with a focus on recovery – Standing Start was not able to seek approval from the SCI centres in the UK. This was problematic for the new directors at Standing Start because they were trying to fill an identified need for community rehabilitation after discharge from SCI centres. As Paul (Director) explained, this called for discussion with the SCI centres, “Everyone agreed community rehab is an unmet need, so what was the problem here? I knew they were not happy with the message Standing Start was putting out, or the way the product was being packaged, or perhaps the approaches to rehab. That aside, what did the SCI centres want?” After a year of consulting with local SCI centres, the directors decided that the relationship with Standing Start was tarnished beyond repair. This called for a re-brand.

Standing Start was re-branded as Neurokinex and re-opened as a brand new ABR facility in April 2013 in Watford (Figure 5.1). This led to a clear distinction between the Standing Start Trust (see *www.standingstarttrust.co.uk*), which continues to operate as a charity raising money for people with SCI, and the social enterprise Neurokinex.

⁴ Most of this descriptive information was gained from talks with staff and clients at Neurokinex and the original Standing Start website (www.standingstart.org). Since the re-brand of Neurokinex this website is no longer active.



Figure 5.1: The new facility at Neurokinex⁵

The name Neurokinex was chosen for several reasons. Firstly, this name was approved through consultations with healthcare professionals (HCPs) at a local SCI centre. Secondly, the name Neurokinex was thought to be less emotive than Standing Start. For example, the Standing Start brand – with a strapline *Hope, Believe, Achieve* – was considered to be too provocative. Although the tagline was perceived to be powerful and motivating, it also insinuated the healthcare system wasn't doing enough for people in terms of their rehabilitation potential. Despite an identified need for community rehabilitation, the directors didn't want to use that in their messaging for Neurokinex. They wanted to gain respect from the SCI centres in terms of the service Neurokinex was able to offer people in the community. Therefore the new strapline *Redefining Possibilities* was chosen as Neurokinex was redefining the options for people to continue rehabilitation after discharge from the SCI centres (Figure 5.2). Thirdly, the term *neuro* was used to highlight the focus on neurological conditions. In this respect Neurokinex hopes to eventually offer a service to people with other neurological conditions (e.g. Stroke, Multiple Sclerosis). Lastly, *kinex* was used as a play on

⁵ All images and photography used with the kind permission of Neurokinex.

the term kinesiology and to highlight the focus of ABR on movement and exercise. Following this re-brand, Neurokinex is hoping to open satellite centres across the UK to help address the geographical barrier of the single site location and offer ABR to more people with SCI and other neurological conditions.



Figure 5.2: Neurokinex’s new logo and strapline

5.2 What is activity-based rehabilitation?

ABR, otherwise known as activity-based therapy, is a term inherited from North America and a form of LTPA characterised by intensive exercise programmes. The aim of these programmes is to maximise an individual’s physiological, functional and neurological potential (Jones et al., 2014). At the same time, through regular exercise, ABR is marketed at Neurokinex to improve health and well-being and therefore enhance the quality of life for people with SCI. Accordingly, ABR was perceived by staff at Neurokinex as “intensive physical activity that is stimulating both your working parts and your non-working parts. So the goal is always to be stimulating the nervous system and your musculoskeletal system” (Paul, Director). To achieve these aims, the trainers at Neurokinex put their clients through high-intensity exercise sessions that aim to benefit their everyday lives. As Jemma (Trainer) explains, “Going to a gym and exercising is different to activity-based rehabilitation where they are out of the chair and doing activities that are linked to their everyday lives basically.” For example, these activities include increasing strength and improving balance to assist with activities of daily living (Figure 5.3) and the use of specialist equipment (such as the inbuilt track system with harness) for gait training (Figure 5.4).



Photo: David Roberts, First Presence

Figure 5.3 Strength and balance training at Neurokinex



Photo: David Roberts, First Presence

Figure 5.4 Gait training with the inbuilt track system at Neurokinex

While intense exercise has been shown to improve physiological function in people with SCI, the effects on neurological and functional recovery are inconclusive (Jones et al., 2012; Jones et al., 2014). The underlying mechanism behind theories of recovery from SCI using ABR is neuroplasticity; the ability of nerves to recover or regenerate through repetitive use or movement. The most promising results have been seen in individuals with incomplete SCI with results highlighting the potential of ABR to promote neurological and functional recovery (Harkema et al., 2012; Jones et al., 2014). However, despite the exciting innovations suggested by this research, it has little application to practice at this point. With this in mind, Jordan et al. (2013, p.1037) suggests that the questions for new therapies such as ABR should not be “Does this new therapy restore the function for people with SCI?” Rather, the question should be “How do patients interpret the results of these new therapies?” This question is answered in this thesis as the impact of ABR is explored through the experiences of clients at Neurokinex (chapters eight and nine).

5.3 Summary

This chapter has provided a brief historical overview of the development of the UK’s first ABR centre Standing Start in Cambridge to the new facility Neurokinex in Watford. Furthermore this chapter has examined the decision behind the re-brand and re-launch as providing a more professional community based rehabilitation service for people with SCI, and building more positive relations between Neurokinex and HCPs at SCI centres. Lastly what is meant by the term ABR was explored along with current direction of research in this area. The perceptions of ABR from physiotherapists in UK and Ireland SCI centres are investigated in chapter six. Moreover, the experience of ABR from the clients and trainers at Neurokinex is explored in chapters eight and nine.

Chapter 6: Physical Activity in Spinal Cord Injury Rehabilitation

6.0 Overview

This chapter explores physical activity (PA)⁶ as a component of spinal cord injury (SCI) rehabilitation. Physiotherapists have been identified as the healthcare professional (HCP) best placed to promote a physically active lifestyle to people with SCI (see chapter two). Despite this, there is no research on what physiotherapists in SCI rehabilitation themselves *perceive* about PA for people with SCI and what they feel they *do* in relation to promoting PA. This chapter addresses this absence. An inductive thematic analysis was conducted on the interview transcripts which resulted in the development of three themes. These were: 1) perceived importance of physical activity; 2) inconsistent physical activity promotion efforts; and 3) concern regarding managing hope. This chapter builds upon the knowledge of the factors that promote and constrain a physically active lifestyle for people with SCI as identified in the meta-synthesis (chapter three) by highlighting the role of physiotherapists in PA promotion.

6.1 Perceived importance of physical activity

All physiotherapists recognised the value of PA both in rehabilitation and the community. This included the importance of PA for well-being, physical health, the prevention of future illness and quality of life. For example, in terms of well-being, the physiotherapists highlighted factors that impacted upon a person's subjective (SWB) and psychological well-being (PWB). SWB refers to an individual's perceived happiness and satisfaction with life (Ryan & Deci, 2001; Keyes et al., 2002). In terms of this kind of well-being, the physiotherapists noted that participating in PA was beneficial in improving mood, self-esteem and self-confidence. PWB refers to psychological growth and development (Ryan & Deci, 2001; Keyes et al., 2002). This kind of well-being was perceived also to be promoted through PA by the physiotherapists in terms of their patients having more enthusiasm for life, a sense of purpose, increased social participation, engagement and integration. In addition, the physiotherapists valued PA for its benefit to physical health. This included improved balance, flexibility, strength and cardiovascular fitness. Furthermore they perceived that PA could help in the prevention of secondary health conditions such as weight gain, pressure sores, cardiovascular disease and diabetes in people with SCI. All of these factors were understood by the physiotherapists to positively impact upon a person's ability to carry out activities of daily living, their independence, and ultimately their quality of life. The perceived

⁶ The term physical activity (PA) is referred to in this chapter over leisure time physical activity (LTPA) as the physiotherapists' discussions of PA included both LTPA and elite sport.

importance of PA for health and well-being is encapsulated in the following comment from Andrew:

Physical activity just addresses so many areas of rehabilitation in life. You've got your cardiovascular element of physical activity, getting the heart rate up, as cardiovascular disease is the biggest killer of spinal cord injured people as well as able-bodied people nowadays. So you have to find ways to encourage and promote physical activity for cardiovascular fitness because patients are living longer, they're going to have these problems when they're older; they need to be educated about it now. Strength that you get from physical activity is insanely important. In inpatient rehabilitation there is a lot of functional and practical skills to learn, if you take transfers for example. And you can teach, and teach, and teach correct technique and patients will pick it up and they will know what the correct technique for transferring into a car is say. But they won't master it until they've got the strength in order to do that technique.

The physiotherapists in this study therefore recognised the value of PA beyond the medical model of disability which typically prioritises physical and functional restoration outcomes (see chapter two). Resounding with research on SCI rehabilitation and PA in other countries (Mulligan et al., 2011), the physiotherapist viewed PA through a social relational model of disability (see chapter two). This was evident as they recognised the importance of PA participation for promoting health and well-being including independence, social integration and quality of life.

The knowledge that PA can be important for health and well-being was predominately gained through the practical or experiential experience of caring for people with SCI over time. This type of practical and embodied knowledge is known as *tacit knowledge* (Ferlie et al., 2014). With the rare exception of four people who had chosen to take further education (MSc and PhD), the value of PA was learnt through seeing the perceived detrimental effects of physical inactivity. For example, all physiotherapists had witnessed people with SCI return to the rehabilitation centre months or years after leaving due to illness or secondary health conditions. They perceived that these could have been avoided, and thus readmission to the hospital prevented, by people with SCI being active in the community. Physiotherapists also perceived that many people who were readmitted to rehabilitation had poor SWB and PWB. Without claiming any causality or that PA is a panacea, they felt that poor well-being could have been prevented or helped through being regularly active. In addition to experiential knowledge, some physiotherapists also identified their own bodies as sources of knowledge

about PA. That is, for some people their practical knowledge of the importance of PA was reinforced by their own embodied experiences of being physically active.

Notwithstanding the value of experiential and embodied knowledge, participants revealed that they had a limited range of other sources of PA knowledge. For example, most said they did not access peer-reviewed academic papers, web-sites, or evidence based health policy documents promoting PA. Participants also stated that they were not educated on PA during their degree course or through any workshops. Therefore the participants did not gain any *explicit knowledge* through training (Ferlie et al., 2012). As Vicky commented:

The problem is physios are not trained to properly fitness train a patient. A sports therapist may have learnt to get someone fit, but I believe in SCI there are not many physios who can just take a patient to the gym and give them fitness training that would work for them. There are not many who could do something just like that; it is something they need to learn. It is not part of their obvious route. It is not yet in the culture that PA is something the physios should be doing.

6.2 Inconsistent physical activity promotion efforts

Despite knowing the importance of PA through a limited repertoire of sources, and having seen the consequences of an inactive lifestyle on the health and well-being of people with SCI, active PA promotion was not a structured or integral component of most of the physiotherapists' practice. Only a minority of physiotherapists (4 participants) both valued the importance of PA and reported actively promoting PA. This active PA promotion included encouraging their patients to attend available PA opportunities, educating them on the benefits to well-being, physical health, prevention of secondary health conditions and quality of life that can come with being active, and prescribing PA programmes to allow patients to exercise independently. All of this was promoted not just in the short term. The small group of participants also highlighted the importance of promoting PA when people left rehabilitation and went back into the community. These physiotherapists were knowledgeable about PA opportunities including both sport and exercise in the community and were able to offer guidance on how often people should be physically active to achieve lifelong health and well-being benefits. The attitude towards PA promotion and how physiotherapists can actively promote PA in rehabilitation is illustrated by Jack:

I think we as physios, we are best placed to be the ones to educate and advise and encourage our patients to take part in physical activity. I mean there's amps of literature out there which supports how beneficial it is. There's literature out there to

support that the messages and education we give spinal cord injured patients in their first few weeks of rehab tend to stick with them, so we need to make sure that we are honing in at that window of opportunity to install some education and physical activity ethos in our patients. And physios of course are the best people to be doing that, we have the knowledge about cardiovascular benefits, strength benefits, all the different benefits. We... help support and encourage them to look up websites and sporting clubs around them, and educate them on graded exercise programs. And providing the opportunity to get in a sports chair, or play a certain sport or be introduced to different people. So that's our role as physios and we have to start incorporating that into our rehabilitation process, our rehabilitation management.

There were therefore a minority of participants that both understood the value of PA and actively promoted it. However, the vast majority of participants did not actively promote PA. These physiotherapists were very limited in their PA promotion practices, and in some instances PA promotion was completely absent. That is, translating the importance in the everyday rehabilitation setting and PA in the community was neglected. For example, if PA was briefly mentioned, no specific information about the types of PA, amounts and intensity of PA to achieve desired health benefits, or where to be active once in the community was said to be offered. Furthermore, whilst there was much variance among how physiotherapists defined PA, sport was both often equated to PA and viewed as the only PA option for people with SCI. For higher level injuries and patients with tetraplegia, stretching was considered as adequate PA for this population.

There were various reasons for why the promotion of PA was neglected both within rehabilitation and within the community. One reason why most physiotherapists failed to promote PA was because it was deemed, contra to the views of many people with SCI, to be not part of their role. For some of them, it was down to the patients to become experts and masters of their own rehabilitation. As physiotherapists, they would try and foster patient autonomy by encouraging people to investigate PA opportunities by themselves. Moreover, physiotherapists largely considered the promotion of PA to be part of other HCPs and health practitioners' role within rehabilitation. These included other HCPs such as sports physiotherapists, and health practitioners such as sports therapists, personal trainers, or sport and exercise scientists based in the gym. Some physiotherapists perceived that these HCPs and health practitioners were best placed to actively promote PA because they had the expertise in sport and exercise. However, this was only an assumption as it was not always explicitly discussed as to whose role and responsibility it was to promote PA:

Interviewer: do you promote these (physical) activities to your patients?

Martin: I don't personally, I leave that to the physios who worked in exercise therapy to do that. I would talk to them (patients) about it obviously initially, tell them what happens and that I'm going to refer them there. And I always tell everyone they should give it a go at least once.

Interviewer: is there any reason why you don't promote physical activity?

Martin: well I suppose maybe just because my own role as a physio is to not to work with them towards cardiovascular goals, it might be more focused for instance towards working towards mobilisation with a gait aid or upper limb function of some sort. But I tend to leave it to the physios in exercise therapy to deal with... It doesn't really occur for me to do that and it's never been a part of what we would do. It's more to do with the physios who work in sport. Not that it's their job to do it, but they tend to do it more than we would. In fact, we wouldn't really do that at all.

A further reason offered as to why PA was not promoted revolved around barriers to PA promotion. Regardless of whether the participants actively promoted PA or not, in rehabilitation these barriers included limited or no on site sport and exercise facilities, no staff resources to take patients to a gym if available, a lack of support from the multidisciplinary team in rehabilitation, and very limited funding from the healthcare system to support PA initiatives. There was a sense of frustration from the physiotherapists in regards to these structural barriers as they were perceived to be out of the physiotherapists' control. As indicated earlier, physiotherapists also felt they lacked training in exercise prescription. This led to an absence of any systematic processes in place to establish exercise programmes for people to carry out independently in the gym. Patients could access the gym if one was available in the context of rehabilitation but they wouldn't have a safe and useful exercise programme to follow. Furthermore, some of the physiotherapists held certain perceptions about their patients that prevented them from promoting PA. For example, there was a perception that not all patients, especially those with higher level injuries and subsequent paralysis, would want to see others with less paralysis and more function participating in sport. Consistent with research in stroke rehabilitation (Morris et al., 2014), the physiotherapists in this study perceived they were unable to change behaviour and motivate those patients who had little interest in PA. This is despite the important role of behaviour change in fostering adherence to treatment plans in physiotherapy practice (Jack et al., 2010; Heaney, 2012; McGrane et al., 2015). The attitude of the physiotherapists in this

instance was that PA was not for everybody and it is fine if people choose not to be physically active:

Sarah: There are such a range of patients. There are some patients that are always down the gym in between sessions, always working really hard. And then there are others that you just never see other than occasionally in their one-to-one session. And then it's like how do you get to those patients that aren't really doing anything? And then it's hard because there is part of me that thinks well they might never have been to a gym before. Even before all this, they weren't that bothered. They might not necessarily feel like that now. I think there's a limit on what you can do, if they're not bothered what are you going to do to make them do that (physical activity)?

In addition to the barriers of PA promotion in rehabilitation, there were also multiple barriers that hindered PA promotion within the community. These barriers to promoting regular PA in the community involved a lack of knowledge regarding where to be active and what PA opportunities were available, a concern over the cost to be physically active and a perceived lack of support in the community for people to be physically active. For example, some of the SCI centres had patients from a very large geographical area. In this instance the physiotherapists' felt they lacked the knowledge about where people could be active if they wished and the different PA opportunities within their large patient catchment area. Furthermore, the physiotherapists were concerned over the cost of personal PA equipment (such as functional electrical stimulation) that they perceived was the only option for patients with higher level injuries to be physically active. If they were aware that their patient did not have the financial resources to access such equipment, then this would prevent them from promoting PA.

Furthermore, echoing research in the UK (Walkeden & Walker, 2015) and other countries such as Sweden and New Zealand (Mulligan et al., 2011), the physiotherapists located multiple barriers to PA promotion within their healthcare system. For example, the physiotherapists raised concerns that there was an absence of people embedded within the community to help people with SCI become physically active. Currently, patients are only referred to community physiotherapy upon discharge from the SCI centre if they have functional goals to work on. These community physiotherapists are not specialists in SCI and were deemed unlikely to know about safe and useful PA opportunities for this population. As Emma commented:

They (people with SCI) just can't get to these things and it falls down and I don't think therapists in the community are ever in a position to go "fitness and health is actually a medical treatment for this guy so we should be facilitating him to get to a gym." If we had GP prescription we'd be putting them all on it to say here is a programme for the gym you go three times a week... And what I keep challenging the lead on is that we don't have the accessibility when a person leaves hospital to allow them to continue on and finish their rehab.

The inconsistent PA promotion efforts from the physiotherapists in this sample highlight the lack of structured and embedded PA promotion practices across SCI centres in the UK and Ireland. The physiotherapists' perceptions about PA promotion also reveal a lack of clarity and support within the healthcare system as to the roles and responsibilities of professionals in health promotion. According to the World Confederation of Physical Therapy, physiotherapists have been hailed as the health-promotion profession (WCPT, 2012). Further they claim "physiotherapists use the health promotion approach of participation and empowerment in their treatment of people and groups to improve their lifestyles and health through physical activity" (p.16). However, this was not evident in this study as not all of the physiotherapists considered their role to include health promotion through PA.

6.3 Concern regarding managing hope

When discussions turned towards community based PA options, the physiotherapists' expressed their unease with how these centres managed hope regarding physical recovery following SCI. In particular, their concern was directed towards activity-based rehabilitation (ABR) centres. ABR is a community based PA initiative whereby people with SCI can pay to exercise with the aid of specialist health practitioners within an adapted gym facility. ABR is characterised by intensive exercise programmes which aim to maximise an individual's physiological, functional and neurological potential (Jones et al., 2014) (see chapter five). At the same time, through regular exercise, ABR is marketed to improve health and well-being and therefore enhance the quality of life for people with SCI. As noted above, physiotherapists recognised the importance of PA within the community and thought that ABR was a good idea in theory. By this they meant that they could see the benefits of a community initiative that facilitated a physically active lifestyle for people with SCI. Moreover, the physiotherapists valued the role community health practitioners in ABR centres could play in re-educating people on aspects of SCI care, health and well-being:

Karen: It (activity-based rehabilitation) could be amazing because it's re-education again and also not only is it re-education but it's revision. When you're in hospital, when you're grieving, you are only learning or hearing 50% if that, of what you are being told. So six months post discharge actually you are looking around probably coming back up from drowning and you can take on board what the therapist is saying.

Despite the positive role that ABR could play in getting people with SCI more physically active, the physiotherapists did not actively promote ABR for people with SCI. They perceived the goals of ABR conflicted with their goals of rehabilitation which lead to greater concerns regarding how hope was managed in this context. The physiotherapists stated their goals in rehabilitation were to teach people with SCI how to live a life that was meaningful to them, and get back to an active, happy, and independent lifestyle as soon as possible within the community. To do this, working on functional goals, such as transferring skills, was promoted. The goals of ABR were perceived to focus on activities that were not functional, such as gait training and assisted walking, neglecting the promotion of an independent lifestyle. This was problematic for the physiotherapists because they perceived ABR to be promoting what is termed a restitution narrative. The restitution narrative in this context refers to a common storyline in SCI that follows the plot "yesterday I was able-bodied, today I'm disabled, but tomorrow I'll be able-bodied again" (Smith & Sparkes, 2005, p. 1096). Participants were concerned that ABR centres were promoting, implicitly or explicitly, this narrative when the engagement in intense ABR is connected to functional recovery. For them, this fostered unrealistic expectations and false hope regarding functional recovery from SCI. In addition, promoting unrealistic expectations of recovery through ABR was perceived to lead to people with SCI experiencing in the future psychological distress if recovery was not forthcoming. The unease of ABR was exemplified by Andrew:

Andrew: We have patients who are complete non-functional patients who think "I'll just go here (to activity-based rehabilitation) and they'll make me walk. I've seen them they get you up in a treadmill and make me walk." You educate them enough to think it's not straightforward like that, it's not like we don't want you to walk so we're not doing it here so if you go somewhere else they will make you walk... But, I think the message has to be very clear and I think considering that the patients, a lot of the patients or people who go there are newly injured people. That you have to be careful because you don't know where down that scale of adjustment and coping they are at and it can be dangerous.

Interviewer: What do you see as those dangers?

Andrew: I guess the dangers to me are that you are misinforming patients of unrealistic expectations and you could be setting them up for a crash. You know they've already had a life changing traumatic event, you don't want them to build all their hopes, all their expectations, spend hundreds of thousands of pounds potentially on a potential false hope.

The lack of understanding regarding PA initiatives such as ABR highlights a breakdown in communication between the physiotherapist in the SCI centres and the health practitioner in the community. Despite reservations concerning how hope and expectation is managed in ventures such as ABR, the physiotherapists in this study, by and large, did not make a concerted effort to investigate ABR as a viable PA option for their patients. In line with the social relational model of disability that highlights the social imposition of restricting activity for people with SCI (see chapter two), not promoting PA through ABR could be viewed as a form of social oppression. The physiotherapists were enacting psycho-emotional disablism (Thomas, 2007) by denying their patients the option to remain physically active through ABR.

6.4 Summary

The purpose of this chapter was to explore what physiotherapists *perceive* about PA for people with SCI and what they feel they *do* in relation to promoting PA. A significant finding was that despite physiotherapists understanding the value of PA for people with SCI, health promotion through PA remains largely absent within the UK and Ireland rehabilitation context. This is an important finding in this thesis considering that physiotherapists have been identified by spinal cord injured people as trusted and valued messengers of PA (Letts et al., 2011; Smith, 2013), and physiotherapy being hailed as the ideal profession to promote, guide and prescribe PA (Mulligan et al., 2011; WCPT, 2012; McGrane et al., 2015). Accordingly, there were several factors that impacted PA promotion. Firstly, this chapter identified a lack of formal training and education in sport and exercise to enable all physiotherapists to effectively promote and prescribe PA to people with SCI. Secondly, this chapter highlighted a lack of clarity and support within the healthcare system as to the roles and responsibilities of physiotherapists in PA promotion. Thirdly, the physiotherapists perceived that they did not have the required skills to change health behaviour and motivate people to be physically active. Lastly, the physiotherapists did not communicate with health practitioners in the community to enable them to make informed decisions regarding PA initiatives such as ABR. The implications of all of this are brought together in the final chapter

(ten). The next chapter focuses upon the issue raised by the physiotherapists regarding the potential false hope of ABR and explores how physiotherapists manage hope and expectations of SCI rehabilitation.

Chapter 7: Managing Hope and Expectation in Spinal Cord Injury Rehabilitation

7.0 Overview

As highlighted in the previous chapter (six), avoiding false hopes of functional recovery was an important concern for the physiotherapists during their patients' rehabilitation following spinal cord injury (SCI). The physiotherapists' concern stemmed from the perceived psychological damage that could occur if unrealistic hopes of SCI recovery were not realised by their patients. Given the importance of this, this chapter address *how* physiotherapists manage hope and expectation throughout rehabilitation to try and drive realistic hopes of SCI rehabilitation. Firstly, I will introduce the notion of *therapeutic emplotment* used by the physiotherapists to create clinical experiences in rehabilitation that shaped the way patients experienced hope. Therapeutic emplotment is an interpretive activity whereby story-like structures are created through therapist-patient interactions which plot "therapeutic actions within a larger therapeutic story" (Del Vecchio Good et al., 1994, p.855). Furthermore, within therapeutic emplotment, narratives become 'tools' in the hands of therapists to shape their interactions with patients and construct a meaningful story of rehabilitation for both therapist and patient (Mattingly, 1994; Tropea, 2012). Storytelling therefore becomes a significant action to guide rehabilitation in a particular direction and towards particular goals, to try and connect a patient's individual experience to preferred narratives (Mattingly, 1998). Secondly, I will describe the *strategies* that the physiotherapists drew upon to guide therapeutic emplotment to create a plot and set the story in rehabilitation towards realistic hopes of SCI rehabilitation.

7.1 The therapeutic emplotment of acceptance

Following a sudden and traumatic SCI, people typically need to go through a process of adaptation and adjustment to reconstruct their life story to accommodate a new body (Day, 2013; Dibb et al., 2013). To facilitate this process of narrative reconstruction, the physiotherapists in this study were primarily concerned with their patients' ability to *accept* their injury. In this context, acceptance is understood as an important psychological end point in neurological rehabilitation whereby a patient has accepted their current situation and has realistic hopes and expectations for the future (Soundy et al., 2010; Soundy et al., 2014b). Hope is a personal and complex phenomenon but is generally recognised to reflect how a patient accepts their present situation and considers their future (Soundy et al., 2013; Stempsey, 2015). Narratives are therefore an important consideration in neurological rehabilitation as patients' narratives often revolve around their hopes (Soundy et al., 2013). Therapeutic emplotment is one way in which therapists can guide a patient's story and hopes

to create a plot structure within the clinical time of rehabilitation (Mattingly, 1994). An integral component of therapeutic employment is that the therapeutic actions of the therapists in rehabilitation are plotted within a larger therapeutic story (Del Vecchio Good et al., 1994). For the physiotherapists in this study, their therapeutic interactions in rehabilitation were favouring a plot structure of acceptance.

Echoing the multiple meanings of acceptance for patients with SCI (Dibb et al., 2014), acceptance was articulated by the physiotherapists as patients coming to terms with, dealing with, adjusting or coping with the SCI. The notion of acceptance was conveyed as patients changing the focus of their rehabilitation away from recovery or cure from SCI, towards problem-solving for their lives to continue. An important component of this story was that patients understood the severity of their injury and the multitude of consequences (both personally and socially) this would have on their lives. This was exemplified in the following comments by Karen:

But it's just that, what I need to see is that the patient has realised the severity of the situation, that life has changed dramatically and the time I start to realise that they have realised is when they start asking questions that are more realistic about their future. So a patient may start asking me about how they are going to get themselves into town. And that is quite interesting rather than a patient assuming they are going to drive their car in to town. So eventually you hear a patient change and they may come and say to us I need to be able to do this. So that is when you start to hope that the patient understands the situation.

The ability of patients to accept their injury and understand the severity of the impact on their life was perceived as crucial to their engagement with rehabilitation. One of the dilemmas identified by the physiotherapist was the restricted time in which they were trying to bring about acceptance in their patients. On the one hand, physiotherapists have been called to *allow time* within rehabilitation for patients to express emotions surrounding the loss associated with neurological conditions (e.g. their job, social role, identity, previously valued activities) (Soundy et al., 2012). Furthermore, this call extends to physiotherapists to *take time* to listen to a patient and understand what acceptance means to them (Soundy et al., 2012; Soundy et al., 2014a). On the other hand, a vital purpose of rehabilitation is to teach people how to take care of a changed body and live independently with SCI so that they can achieve optimum health and well-being when they are discharged back into the community. The actual time physiotherapists have with their patients to teach these skills has been dramatically reduced from a period of months (up to a year) to that of only 12 weeks (Levins

et al., 2004; Letts et al., 2011). Therefore for the physiotherapists it was deemed crucial that their patients' had accepted their SCI *as soon as possible* after admission to the SCI centre so that they were emotionally ready to learn these skills.

Typically patients were characterised by the physiotherapists as non-accepting when they remained focused on rehabilitating their legs, spoke only of recovery and refused to engage with wheelchair skills. Accordingly these patients were telling a story of restitution whereby the storyteller is seeking to restore their previous healthy and able-bodied selves and identity (Frank, 2013). Their hopes for the future, as framed by restitution, were *concrete hopes* of recovery from SCI. Concrete hopes are associated with specific hopes of a cure from SCI and a restored body-self (Smith & Sparkes, 2005). These concrete hopes were distinguished by the physiotherapists as unrealistic and false hopes (Soundy et al, 2010). Furthermore, due to the debilitating nature of SCI, these hopes were considered to be counterproductive and constraining to a patient's rehabilitation and ability to narratively reconstruct their lives (Smith & Sparkes, 2002; Smith & Sparkes, 2005). The danger with concrete hopes is that patients can risk limiting the quality of their life as they put their life on hold working towards goals that are not realistically going to come to fruition.

On the other hand, the physiotherapists characterised patients as accepting of their injury when they took an interest in their rehabilitation, tried to achieve more on their own and asked questions about the practicalities of living in a wheelchair. In contrast to restitution, these patients were perceived to have realistic hopes and expectations of rehabilitation and what life would hold for them outside of the context of rehabilitation. These patients were instead drawing on aspects of the quest narrative as they were seemingly on the road to accepting their impairment and associated disability. For Frank (2013), quest stories are more than just accepting illness or injury. In the case of SCI, they tell of searching for alternative ways of being disabled, meeting suffering head on and seeking to gain something from the experience. Furthermore, the quest narrative fosters *transcendent hope* which embraces the unknown and provides a narrative scaffold that allows the teller flexibility to adapt to an uncertain future (Smith & Sparkes, 2005). The physiotherapists were more comfortable listening to stories that hinted at the beginning of a quest into disability, than they were hearing prolonged accounts of restitution and concrete hopes of recovery.

All this said, portraying acceptance did not mean that the physiotherapists believed that patients could not have hopes of a recovery in the future. As Soundy et al., (2012) note,

following the transition to acceptance, the patient's hope can indeed change from that of cure to a change in symptoms that should not to be confused with unrealistic hope. Most of the physiotherapists in this sample assumed that patients hoped to get back to their former self before experiencing a SCI. Furthermore, in line with research across neurological conditions (e.g. stroke, brain injury), the physiotherapists' perceived having hopes of a better future was a normal and healthy attitude to life and a key motivator during rehabilitation (Soundy et al., 2010; Soundy et al., 2012). In other words, the physiotherapists accepted the patients' *right to hope* (Groopman, 2005). Furthermore as Smith and Sparkes (2005) propose, people should not be denied the right to tell restitution stories because concrete hope can play an important role in the process of coping with SCI. Indeed, false hopes of recovery can be valuable for keeping the patient positive and engaged in rehabilitation (Soundy et al., 2010; Nunnerley et al., 2012). However, the crux of the matter for the physiotherapists was that although their patients could have (unrealistic) hopes of SCI recovery, they needed to accept their injury and have realistic expectations of what they were likely to achieve from rehabilitation:

Jack: Some people are extremely practical and when you are doing your initial assessment their hope will be to be able to be as independent as possible. To be able to get into their wheelchair, and push their wheelchair. Then there are other people who will be quite unrealistic and want to return to playing rugby, or return to sprinting or whatever it might be. I suppose you do find differences in it but a lot of it is down to the individual I guess, I suppose. Things like, quite subjective things like maturity level, drive motivations. People are determined in the face of things that they are going to prove everyone wrong and show everyone that this is going to happen. I think there is a subjective element but also I think realistically everyone hopes to get back to as close as to where they were before and that is not going to be achievable for everyone. So I'm sure some people whose hopes and expectations are sky-high don't achieve either. But I suppose expectations, that's what we have to try and manage... Maybe people whose expectations are sky-high, trying to maybe, I don't want to say bring them down, but maybe make them a little bit more realistic and explain to them.

This position regarding hope and acceptance whereby the patients hope for an outcome such as cure from SCI, yet expect that realistically a cure is unlikely, relates to the paradox of chronic illness. In this paradox, patients “defy limitations in order to realise greater life possibilities and... accept limitations in order to avoid enervating struggles with immutable constraints” (Barnard, 1995, p.39.). In other words patients can accept their SCI, yet at the same time try to defy it. For Soundy et al., (2013) this represents *hope in possibility*

where the patient is prepared to accept that what is hoped for may not occur. Therefore hope in possibility is central to the paradox “as it simultaneously incorporates the apparently contradictory positions of acknowledgement (which is an essential component of adjustment and leads towards acceptance), and allows the patient to have a defiant attitude” (Soundy et al., 2014a, p.258). The paradox also represents a position whereby the patients are caught between the “boundary between old formations of self and new formations not yet born” (Barnard, 1995, p.50). It is during this paradox that illness narratives can perform a vital role in the process of narrative reconstruction and enable patients to engage with different hopes (Alaszewski and Wilkinson, 2014). However, the physiotherapists were able to allude to this paradoxical position of hope in SCI and did not perceive this position to constrain rehabilitation when so called unrealistic hopes were balanced with realistic expectations. In this situation patients’ draw upon other illness narratives than restitution or quest as neither of these allow for both acceptance and defiance (e.g. heroic, detective, ironic narratives [Soundy et al., 2013]).

Furthermore this study highlighted a conceptual distinction in the physiotherapists understanding of hope. Although not articulated as such, the physiotherapists were referring to the difference between hope as expectation (anticipating an outcome that is *likely* to occur e.g. realistic expectations of rehabilitation) and hope as want or desire (likelihood of occurrence is *remote* e.g. defiance through hoping to walk again) that is often overlooked in the literature concerning hope (Wiles et al., 2008). In addition, the physiotherapists recognised a temporal dimension of hope as it changed throughout rehabilitation (Wiles et al., 2008; Soundy et al., 2010; Soundy et al., 2014b; Van Lit and Kayes, 2014). Changes in hope bring about changes in narrative, just as changes in narrative reflect changes in hope, as patients re-construct their identities through telling stories (Mattingly, 1998). In neurological rehabilitation, Soundy et al. (2013) proposed that patients typically move through an established pathway from hope as dichotomy (concrete hope or no hope), through hope as a paradox towards acceptance and transcendent hopes.

The physiotherapists in this study identified a similar, but different, pattern of change in hope that was a key process in the therapeutic employment of acceptance. These changes in hope during rehabilitation were perceived by the physiotherapists to be brought about by a *moment of realisation*. This moment of realisation was articulated as a time of significant impact, an emotional moment or an outcome of a lack of progress during rehabilitation. Thus, moments of realisation were an essential consequence of therapeutic employment as they

moved the plot of the story forward and represented a shift in narrative from stories aligned with restitution to those representing defiance or quest. The result of these moments was that patients were forced to reassess their goals of rehabilitation and associated hopes and expectations as they realised the severity of their injury or their situation.

The physiotherapists recognised that although each patient was different, these defining moments were likely to occur at certain stages during rehabilitation. These included, but were not limited to: the first time a patient gets up from bed rest and sees their paralysed and often atrophied body; the diagnosis and prognosis meetings with the medical team; sudden or unexpected changes in symptoms; the first time a patient is transferred into a wheelchair and realises this might be for life; and when a patient is being discharged and realises they haven't achieved all they have hoped and that they might need care. However, the following extract from Sophie demonstrated how these moments of realisation could be triggered by any event during rehabilitation:

Sophie: there was a moment yesterday when a patient came to the realisation of how severe his injury is.

Interviewer: can you describe this moment?

Sophie: I can down to a T. So he was very sporty previous to his injury and he was a very talented football player and it just so happened that a patient on the bed next to him was doing therapy with the football. Just a ball, and handed it to him. He was practising his transfers and his leg management and as soon as he got the ball, he just kind of, reality dawned and he became really upset about it. The realisation of it all. That's tough because he was out in the open gym, he was physically upset so, there was not a whole lot we can do to take him away because he can't transfer because he's upset and he needs assistance. So you just have to be there for him and just hear him out and have a little chat. So in that scenario he was very much down for the day and he's still even down today but at that moment in time he wasn't going to have psychology, he wasn't going to have social work or counselling sessions. So you can't just leave them there, in mid-treatment you have to do step up and try and do what you can. But sometimes it's hard to know what the right thing to say is because at the end of the day he is how he is and for him unfortunately it is not going to change.

As Sophie insinuates, these moments of realisation could be particularly harrowing for their patients. For some patients, as illustrated above, realisation was conceptualised by the physiotherapists as a lightbulb moment. In this instance the patient came to realise in one traumatic moment that his life had changed forever. For other patients, this realisation could

come over time as they progressively started to comprehend the severity and impact of their injury. Regardless of how patients experienced this moment of realisation, it was more often than not perceived by the physiotherapists as distressful for the patient. In other words, it was experienced by patients as a moment of chaos (Frank, 2013). The chaos narrative imagines life never getting better and is associated with *despair* and *loss of any kind of hope* (Smith & Sparkes, 2005). Although the moment of realisation and ensuing chaos was distressing for both the patients and physiotherapists, it was perceived by the physiotherapists to be a necessary part of rehabilitation on the journey to acceptance. The therapeutic emplotment therefore involved guiding patients through this moment of hopelessness and chaos so they could accept their SCI and recalibrate their expectations to more realistic outcomes (Soundy et al., 2013). For some patients this was described by physiotherapists as a linear process, whereas other patients would go through cycles of despair as they repeatedly tried and failed to defy their SCI.

It was recognised by all physiotherapists that when a patient loses hope in recovery, other hopes must be found. Thus, once the patient is able to move out of chaos, they can focus on an *active* type of hope whereby the process of acceptance is followed by active engagement in other fulfilling activities (Arnaert et al., 2006; Soundy et al., 2010). In order to establish this active hope, and turn away from restitution or chaos towards a quest narrative, patients need to re-establish a sense of purpose and find a new direction for their life (Hammell, 2007; Soundy et al., 2012; Dibb et al., 2013). Active hopes are welcomed by physiotherapists and considered the correct way to engage in narrative reconstruction (Soundy et al., 2013). Active hope can lead towards hope in possibility because the source of hope is adjusted from a medicinal or technological cure towards taking action against SCI. Therefore patients can accept their injury but take action by trying to defy it (Soundy et al., 2013). On the other hand, patients may express active hope that transcends SCI as they embrace other life values over physical improvement.

The therapeutic plot of acceptance created within SCI rehabilitation can thus be summarised as follows: “*The patient experiences a SCI and can hope for recovery. But through rehabilitation, the patient needs to experience a moment of realisation where they accept their injury and focus on realistic expectations of SCI rehabilitation.*”

Critical reflections: Box 7.1 Re-writing the story

To guide my analytical thinking about the story the physiotherapists were trying to emplot during rehabilitation, I tried telling the story from an observer's point of view. This is one of the acts of interpretation Frank (2010) suggests that can guide "movement of thought" in a dialogical narrative analysis (DNA). I started drawing (Figure 7.1) the plot of acceptance as I interpreted the process of therapeutic emplotment as guiding patients through a moment of realisation. I imagined hope moving on a continuum (unrealistic < > realistic < > no hope) and where the associated narratives (restitution, defiance, quest and chaos) would be labelled. This illustration helped me structure the chapter as I saw the therapeutic plot of acceptance unfold. I thought it was important to first describe and define the key features of therapeutic emplotment, what acceptance meant to the physiotherapists and what they perceived as realistic and unrealistic hopes. Then I aimed to identify the strategies (or therapeutic actions) the physiotherapists drew upon to guide the therapeutic emplotment process.

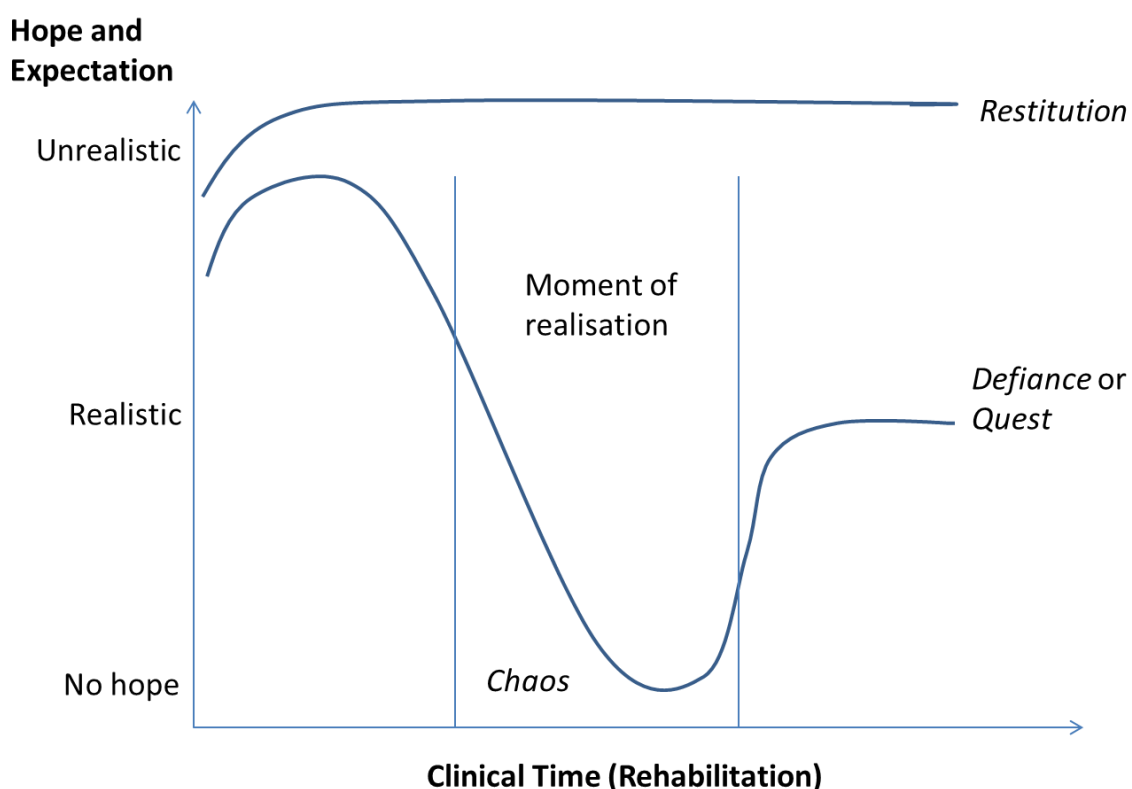


Figure 7.1: Initial illustration of the therapeutic emplotment of acceptance

This chapter has so far illustrated that "hope is not a free floating aspect locked in people's mind" (Soundy et al., 2010, p.85). Rather it is embedded in interaction with the physiotherapists and developed through communication of narratives that seek to provide new stories by which patients can live their lives by. Therefore this chapter now turns

attention to the therapeutic actions the physiotherapists drew upon to guide therapeutic emplotment towards acceptance to manage hope and expectations.

7.2 Therapeutic actions to manage hope and expectation

As stated above, physiotherapists in neurological rehabilitation play a crucial role in helping the patients acknowledge and accept their situation. However this is not an easy task when they are faced with a delicate situation whereby they need to balance patients' false hopes with realistic expectations (Soundy et al., 2010; LeRoy et al., 2014). The physiotherapists in this study spoke of the difficulties they experienced in having a duty to be realistic with their patients whilst trying not to shatter their hopes. With this in mind, they employed four different strategies throughout rehabilitation to manage their hopes and expectations and facilitate acceptance of their injury. These were: careful use of language; goal setting; letting them try, letting them fail; and, reinforcing messages.

7.2.1 Careful use of language

The process of managing hope and expectations within SCI rehabilitation started as close to the onset of injury as possible. In some instances this process began before the patient was even admitted to the SCI centre. For example, some SCI centres had an outreach service where experienced members of staff visit patients in the acute hospital. During these visits the staff member sets the scene and explains to the patient what is likely to happen at the SCI centre. However, this practice was not common across all SCI centres. In many instances the patient could build a picture of the SCI centre as a miracle place that would cure them before they had even arrived. For this reason, the physiotherapists preferred their patients to come to the SCI centre as soon as possible. Once a patient arrived, they completed various assessments and had a diagnosis and prognosis meeting with their consultant. This may have been the first time that the patient is fully made aware of their situation, the consequences of their injury and what they can realistically hope to achieve. To try and reinforce these realistic expectations, the physiotherapists were faced with the dilemma of being as honest with the patients as they can, whilst not crushing their hopes. One strategy utilised by the physiotherapists was their careful use of language:

Phoebe: So you would go through what level of injury and explain why they are categorised that way and how, if you are AISA 'A' that *suggests* that you are complete. It's the wording; it's not what you say it's how you are saying what you are saying. *At this stage* you are a complete lesion with no power, *which is not to say that will stay the same*, we would have to manage your situation with *how you present*

right now. We try and put it on a breaking bad news and providing information. We would then go on to say with that diagnosis it is *likely* that you will be a wheelchair user, and depending on the level *you may be* independent and totally able to care for yourself from a wheelchair. That means if you want to live on your own you could, you can still be a mother, you can still have children, you can go back to work and drive yourself. For some of those people delivering that, you are putting keywords like it is *unlikely* that if your *situation stays the same as it is now*. Then you are trying to be realistic. For some of those that won't be independent you might say, it's *likely* that you might need a power chair, you *might* need care, it is *likely* that you *might* need care to support you in your personal needs. So we try and say early on to manage the expectation.

As illustrated by Phoebe, one way in which the physiotherapists addressed their patients' initial hopes and expectations of SCI rehabilitation was through their careful use of suggestive language concerning hope. As Mattingly (1994) notes, therapists use a number of interventions or actions in therapeutic employment which are directed at setting a story in motion. These actions are emplotted by using a clinical language to transform people's perceptions of a situation (Kohn, 2000). In this instance, this dialogical interaction between the physiotherapists and their patients was aimed to minimise unrealistic hopes of SCI rehabilitation. The physiotherapists referred to *likely* outcomes of rehabilitation based on the patients' level and severity of injury as they presented *at that moment in time*. In much therapeutic discourse and interaction the patient's experience is consciously composed 'in the moment' (Crossley, 2003). This strategy was undertaken by the physiotherapists to instil realistic expectations whilst acknowledging that things *could* change in the future. Therefore the physiotherapists were employing this conversational tactic to offer patients hope in possibility by providing them the opportunity to defy their current diagnosis by engaging in rehabilitation (Soundy et al., 2013). The physiotherapists would furthermore justify the patients' prognosis and therapy plan by drawing on their experiences and telling stories of other patients with similar injuries. This in turn provided the patients with a narrative map of rehabilitation. In this instance the physiotherapists were drawing upon the rhetorical power of narrative to persuade their patients to draw upon certain narratives to reconstruct their life story following SCI (Mattingly, 1998). Furthermore, through their careful use of language, the physiotherapists were able to communicate information in a sensitive, compassionate and empathetic manner. This was important to improve the physiotherapists-patient relationship and create a hope-fostering environment (Lohne and Severinsson, 2005; Kuipers et al., 2014; Soundy et al., 2014b; Van Lit and Kayes, 2014).

7.2.2 Goal setting

Goal setting is an important component of rehabilitation because achieving accessible goals is associated with positive adjustment to SCI (Byrnes et al., 2012; Dibb et al., 2013). As Soundy et al., (2014b) explain, setting goals can help generate a mind-set that is focused on the future. This in turn generates psychological movement for the patient towards positive adjustment. The aim of the goal setting process is for the patient and their family to meet with all members of the multidisciplinary team (MDT) (e.g. Healthcare professionals [HCPs] including consultant, physiotherapists, occupational therapist, nurse, psychologist, speech therapists etc.) to set goals for the patient for the duration of their rehabilitation (Young et al., 2008; Van Lit and Kayes, 2014). The goals are personalised, but broadly speaking encompass increasing a patient's health and well-being, independence and participation.

With a change towards patient-centred care, the goals should be formulated in collaboration with the MDT (Byrnes et al., 2012). As HCPs hold significant power in medical settings, creating mutual goals can provide patients with agency and a feeling of perceived control over their rehabilitation (Wiles, et al., 2008; Soundy et al., 2014b). Moreover, the therapeutic story can only be described as a process of therapeutic employment when the therapist and patient construct a story of rehabilitation *together* and reach a *shared* view of the role of therapy (Tropea, 2012). However, more often than not, the physiotherapists expressed this was not the case. Firstly, the patient may not have any idea what they need to be able to achieve, or capable of achieving with their newly injured body. Secondly, for patients with complete spinal lesions (see chapter two), the goals of their rehabilitation are pre-determined from international guidelines of what a person can achieve with varying levels of complete injury. Drawing upon a list of pre-determined goals to set goals for a patient can be seen as prescriptive and inhibiting of further discussion (Young et al., 2008). However, the physiotherapists described how the MDT used these internally known predicted outcomes for complete SCI and were reluctant to deviate from these goals. Thirdly, physiotherapists felt that a patient may not engage in the goal setting process or have the confidence to speak out, and therefore they would just be told their goals. Lastly, the patient might only be focused on a goal that physiotherapists believed was unrealistic. This is often because physiotherapists and patients have different views of what is, or is not, realistic resulting in a goal disparity (Wiles et al., 2008). In this case, the physiotherapists utilised the goal setting process to acknowledge these goals but try and steer patients towards more realistic expectations:

Lauren: I think if people have unrealistic hopes we try and manage them through the goal setting process. Some patients they struggle to rehab at the time when they are in the rehab unit because they haven't accepted that they might have to do things in a different way to how they did it before. So definitely get people who aren't interested in learning how to transfer or to get their legs on and off the bed because they don't see that that's going to be useful to them. They are still holding out hope that they are going to make a really full recovery. So we say, we understand ultimately you would like to walk but what we need to do is break it down into much smaller goals. The first thing is for you to be able to get standing. So you set that as a two-week goal and then progress to the next stage. So hopefully they can see as well how well they are or aren't progressing towards something and come to their own conclusions.

As Lauren explained, the employment of goals was perceived by physiotherapists as a crucial component in managing hopes and expectations. The physiotherapists placed a great emphasis on realigning the patient's goals to match their *current* abilities. Therefore, the physiotherapists were only willing to promote a therapeutic plot where the patient desired a realistic goal that the physiotherapists could help them achieve (Mattingly, 1998). However, one of the central questions patients have following SCI is whether they will walk again (Van Lit and Kayes, 2014). Due to the escalation of media and scientific attention on neuroplasticity, training and recovery, more and more people are expecting to walk following SCI (Harvey et al., 2012). As demonstrated by Lauren, if a patient was set on the goal of walking, the physiotherapists would break that goal down into smaller components so that the patient and therapists could work towards smaller, mutually agreed goals. For example, a person needs to be able to stand before they can walk, they need to have good core control and use of their arms to stand etc. In this sense, they could propose smaller more achievable goals of rehabilitation and frame these as working towards the patient's unrealistic goal of walking.

Emplotting smaller, more achievable goals in rehabilitation that aligned with a patient's goals was important to the therapeutic relationship between the physiotherapist and the patient. On the one hand it gave the physiotherapists an opportunity to demonstrate to the patient that their own goals were valued. This is important as patients are in a vulnerable position of being "hurt" when they are not supported in what they hope for (Simpson, 2004). In addition, hope can be lost when HCPs do not take the time to fully understand the patient's identity and appreciate their fears and losses (Soundy et al., 2014b). Furthermore, as Mattingly (1994) explains, therapeutic emplotments which disregards the patient's goal and

narrative sense making in rehabilitation are not likely to succeed. On the other hand, the physiotherapists were encouraging patients to better understand their condition by providing an opportunity for the patients to draw their own conclusions about what they were realistically capable of achieving (Soundy et al., 2013).

A key characteristic of therapeutic employment is that the plot structure negotiated between the patient and therapists is embedded within clinical time (Del Vecchio Good et al., 1994; Mattingly, 1998). The physiotherapists in this study were able to draw upon the goal setting process to embed the narrative plot structure of acceptance within shorter periods of clinical time. For example, a patient's progress towards their desired goals was monitored regularly every couple of weeks. This iterative activity of regular review meetings throughout rehabilitation allowed the physiotherapists to demonstrate to the patient where they were and were not progressing. These review meetings can be potentially painful for patients as they facilitate self-reflection in regards to progress towards desired goals (Young et al., 2008; Alaszewski & Wilkinson, 2014). This review process was vital to maintain the relationship between the physiotherapist and their patients, and keep them engaged in rehabilitation when people reached a plateau in their progress. On the other hand, for incomplete patients, the goal setting process enabled them to fully explore their capabilities when their prognosis was more uncertain (Soundy et al., 2010). Indeed, what can be defined as a realistic hope in patients with an incomplete injury is more difficult to establish due to the nature of their injury (see chapter two) and the uncertainty of how much function they will regain:

Charlotte: And with the incomplete SCI, I don't know I'm quite different I guess. If people have got enough movement, you can be really quite encouraging and I will really try as much as possible for those people. So just making sure that they have lots of sensory input, and lots of movement, and their ranges are maintained, just giving them the best opportunity they can to be as functional as they can. When you reach a point where you go okay, things aren't changing any more. You've had a period of getting stronger, you've plateaued now and this is as good as it's going to get at the moment. That is how we manage what is realistic for that person.

By regularly monitoring a patient's goals and progress, the physiotherapists aimed to help them succeed in achieving some goals but also set realistic expectations for the future. Put simply, the physiotherapists looked to provide *just the right challenge* to produce stories of success and maintain hope in rehabilitation (Mattingly, 1998). As Mattingly (1998) explains "success depends not only on correctly judging the patient's physical abilities but also on assessing his [or her] own internal attitudes toward the disability, toward therapy,

toward the therapists. All this matters in assessing how far any patient will be willing to push himself [or herself], how many risks he [or she] will take, how much failure he [or she] can tolerate” (p.79). The physiotherapists knew what ‘just the right challenges’ were because of their tacit knowledge of SCI rehabilitation gained through their experiences (see chapter six). Typically the physiotherapists avoided setting goals that the patients were likely to fail to achieve. However, when unrealistic hopes and expectations persisted, the physiotherapists resorted to letting patients try and achieve goals they knew they could not achieve.

7.2.3 Let them try, let them fail

While the goal setting process was useful in trying to address unrealistic hopes and expectations, there are some patients that, as perceived by the physiotherapists, remain unrealistic and fixated upon restitution. This was perceived as problematic for the physiotherapists. Having concrete hopes when the probability of them coming to fruition is unlikely can be damaging to patients in the long run (Wiles, et al., 2008). The danger with false hopes and expectations is that the patient can put their life on hold working towards unrealistic goals (Soundy et al., 2010). This risks limiting their quality of life as they are unable to adapt and reconstruct their body-self relationship and identity (Smith & Sparkes, 2005; Soundy et al., 2010). On the other hand, as mentioned above, false hopes and unrealistic expectations of recovery may be a coping mechanism for the patient in the early stages of rehabilitation (Cutcliffe, 1996; Soundy et al.; 2012; Dibb et al., 2013). Destroying a patient’s hopes and dreams of recovery in this instance could be psychologically damaging and leave them with no hope, and therefore no reason to live (Wiles et al., 2008; Soundy et al., 2010). Whilst the physiotherapists recognised this coping mechanism, they felt compelled to try and coerce a moment of realisation when these unrealistic hopes and expectations did not change over time and impeded rehabilitation. The physiotherapists recounted these instances through examples of patients becoming uncooperative during physical therapy and refusing to take part in other rehabilitation activities. These rehabilitation activities included educational sessions and other physical activity (PA) opportunities that are aimed to increase a patient’s health, well-being, and understanding of SCI care. Consider the following example provided by Hannah:

These are verbally aggressive patients, patients that don't turn up to the sessions, patients that are completely unrealistic. So I can give you an example, we have a C4 sensory incomplete patient who was determined that he was going to walk again. And he had a lot of spasms, he didn't want to take his spasticity medication, he also

had a lot of neurogenic pain, but he didn't want to take any pain medication. And we couldn't do anything with him because he was becoming a moving and handling risk because of his spasms. You couldn't touch him because he was in so much pain and it's those, it's when people don't necessarily listen to the advice. Obviously everyone has the right to make an informed decision, but it's when people don't listen to the advice it starts to become detrimental to the other members of staff around them, and the patients.

When unrealistic hopes and expectations impeded upon rehabilitation, the physiotherapists tried other therapeutic actions to guide their patients towards a therapeutic plot of acceptance. As directly challenging a patient's hope and expectations can further disengage them (Soundy et al., 2014a), the physiotherapists resorted to letting the patient try and achieve their goals knowing they would fail. Indeed, repeated failure of a task or achieving little success paves the way for the inevitable feelings of frustration, distress and hopelessness (Wiles et al., 2008; Soundy et al., 2014b). Although this method was described by some of the physiotherapists as cruel and brutal, it was highly effective in bringing patients around to realise that their goals were unachievable. The physiotherapists felt that in these circumstances it was best to allow the patients the opportunity to work towards achieving that goal. In this respect the physiotherapists were demonstrating that they cared and valued the patient's experience as they were doing all they could to help (Soundy et al., 2014b). Then when the patient was unable to achieve that goal, they would hopefully start to accept their SCI and move forward with their rehabilitation:

Karen: And then I would be setting goals with the patient and helping them perhaps realise that their strength isn't improving. So you might do an outcome measure of their muscle strength and you say carry on working on this and let's have a look at how it is in a week's time, let's have a look at how it is in two weeks' time. So hopefully that they would see certain aspects of their progress, physical ability isn't progressing. If they are still adamant that they can stand or they can walk, I have to say very occasionally, I sat somebody and said "Okay stand up, stand up!" And they can't, and then they cry uncontrollably, and I tend to cry too and then they're okay after that because they can't stand. But sometimes, I mean I'm not a psychologist but sometimes I look at the patients and I think they almost need to do that to be able to really grieve. So they really, really tried their hardest, they've really tried to stand up and they can't. They need to break down to be able to grieve. And when you have to grieve you have to break down somehow, cry or something to move forwards.

Karen's story reinforces the perceived importance the physiotherapists placed on emplotting a moment of realisation for patients to accept their SCI. As mentioned above,

once a patient had accepted that certain goals were unattainable, it was imperative to provide a new therapeutic plot and refocus their attention on other goals to guide them through moments of grief, hopelessness and chaos (Soundy et al., 2010). This was essential to keep them engaged with physical therapy. For people who wanted to walk, these other goals may include mastering wheelchair skills so that they were still able to participate in the activities that were of significance to them. On the other hand, for people who wanted to be able to transfer independently, a new goal may include learning to use the hoist. The patient would then still be able to transfer independently, just using other means. By giving the patients other options, the physiotherapists were able to set more realistic, and therefore more achievable, goals. In other words, it was essential to help the patient “buy in” to the ideal of future with SCI worth working for in rehabilitation (Soundy et al., 2010). Indeed, as Mattingly (1998) notes “a therapeutic plot only seduces to the extent that it emerges as an episode in an unfolding life story, gives some hope for a life that is still to be lived” (p.70). In other words, therapeutic success is dependent on the physiotherapist’s ability to set a story in motion that is meaningful to the patient. Moreover, “the task is to create a plot in which the ‘ending’ towards which one strives invokes a sense of what it means to be healed when one will always be disabled” (Mattingly, 1994, p.814). As Soundy et al., (2014b) further contend, physiotherapists can enable a patient to become more hopeful by helping a patient gain a sense of meaning in their life through exploration of hobbies or other meaningful activities.

7.2.4 Reinforce messages

As stated earlier, one of the most emotional moments for a patient can occur when they are approaching discharge. The physiotherapists explained that at the very first goal setting meeting, the MDT put plans in place to discharge the patients based on their predicted outcome of function at that time. For example, if the patient is going to be a wheelchair user, their accommodation needs to be wheelchair accessible. Furthermore, if the patient is unable to care for themselves, they need to have a care provision in place before they can be discharged. If a patient has not accepted their injury by the time they are discharged from rehabilitation into the community, they can be totally unprepared to function in this environment. This is because if a patient expects to be walking upon discharge they can be unwilling to learn wheelchair and transfer skills as they don’t perceive these skills as relevant (Harvey et al., 2012; Van Lit and Kayes, 2014). In the worst case scenario, this neglect to understand and comprehend their situation can lead to declines in health, well-being and quality of life, and possible readmission to the SCI centre. To try and prevent this decline, the

physiotherapists were constantly reinforcing the therapeutic plot of acceptance as they tried to guide patients towards realistic hopes and expectations following SCI. However, as Mattingly (1994) explains, therapeutic emplotment can only be guided by therapists, it cannot be dictated. The patient has to be willing to take up the physiotherapist's storyline. Therefore when the patient did not buy into the therapeutic plot of acceptance, the physiotherapists turned to other people including HCPs, family, friends and peers with SCI. The hope was that these people could additionally reinforce messages concerning realistic expectations and help the patient co-construct a story of acceptance following SCI.

As with instances of no hope (Soundy et al., 2010), the first HCP that the physiotherapist turned to if a patient's hope and expectation remained unrealistic was the psychologist. The psychologists are equipped with a different skill set to try and help patients come around to accepting their injury. However, it was noted among all physiotherapists that those patients in the greatest need of psychology were the ones who didn't attend. Some patients didn't like the idea of talking to a psychologist, whereas others did not perceive a need to use the psychology service. This left the physiotherapists in a difficult situation where they could spend a lot of time "talking things through" with their patients in instances where they felt the psychologist would be better placed to do so. Indeed, a lack of psychological training has been highlighted as an issue in physiotherapy practice (Heaney et al., 2012; Alexanders et al., 2015). Unfortunately the physiotherapists could not refer to psychology without the patient's permission. In this case, they would then turn back to the patient's consultant:

Hannah: If it comes up in a one-to-one conversation and it's an appropriate environment you can say to that person that's not necessarily realistic. You can talk them around it, you can explain your reason why. If they are consistently unrealistic that's when we would be thinking about if they would consent to having psychology. Or if it is becoming a running theme their consultants need to speak to them as the team lead and try and explain their prognosis. And their prognosis and diagnosis will have been explained when they first come to us. But obviously they are given so much information, they don't necessarily take that on board.

One of the perceived causes of patients consistently being unrealistic was that they did not take these messages concerning their situation on board. This is not to say that the patient was ignorant or incapable of listening. Rather, the physiotherapists believed that the patients could be so overwhelmed when they are first injured that they don't hear everything they are being told. Therefore as Hannah demonstrated, they will refer back to the consultant

to reiterate a patient's diagnosis and prognosis if they remain unrealistic about their recovery. The physiotherapists additionally recognised the importance of support from family, friends and peers with SCI in helping patients understand their injury. It is not only essential that patients have these additional means of support, it is considered imperative that everyone supporting and interacting with the patient is reinforcing the *same* message concerning their recovery. Inconsistent messages regarding rehabilitation only serve to leave patients feeling confused and unsure of their prognosis (Soundy et al., 2014b). This is exemplified in the following words from Jack:

I suppose again I would certainly be linking back in with the team in general, to discuss and make sure everyone is saying the same things to the patient. They are not getting conflicting reports from different people because that could feed into it. And just sort of try to explain a clear reason as possible as to why I feel the goal is not realistic or not achievable. I will try linking in with, we have some access to peer support, people come in and discuss issues with people with a similar level of injury. And just expose them to people who literally have gone through what they've gone through before. That might help them in terms of hearing things from someone who is in the same boat. As opposed to hearing things from a professional talking at them. I think again is trying to maybe make it more of a broad area and maybe include the family if they are amenable to it. As to get them in and sit down with them. The same with the families as well because often you sometimes explain at length to the patient, but the families don't know, and are only getting one side of the story. The patients are trying to bring them in and explain to them so that everyone is aware of the plan and what's going to happen and maybe what's less likely to happen and why.

Jack's comments highlight two further points for consideration. Firstly, peers with SCI can offer patients a unique insider perspective on SCI that only those in the same situation can provide. Furthermore they are trusted and valued messengers of advice on SCI and play a crucial role in educating people on living with SCI (Smith et al., 2015). They can share their stories of their embodied experiences of rehabilitation and provide exemplars of what could be achieved following SCI (Hammell, 2007). In this respect they are providing the patient with an alternative story to restitution to live their life by. These alternative stories act as narrative resources for the patients to draw upon to imagining how their future story might play out if recovery is not forthcoming. Furthermore social comparison to others with SCI has been shown as another coping mechanism that can lead to positive adjustment following SCI (Buunk et al., 2006; Dibb et al., 2013). Secondly, it is important that a patient's family are also fully aware of the situation and are not unknowingly filling the

patient's head with false hope of recovery (Smith & Sparkes, 2005). In this respect the physiotherapists have to additionally manage the hopes and expectations of friends and family if they support the patient in accepting their injury.

Whilst the physiotherapists were armed with all of these strategies to manage hope and expectation, they admitted there were some patients that, despite their best attempts, would never accept their injury. In these instances therapeutic employment was unsuccessful. These patients would continue to defy their SCI and challenge their diagnosis at every moment possible. Certainly, it can take up to ten years for patients to accept their injury (Van Lit and Kayes, 2014) and have *no need to hope* for recovery (Soundy et al., 2010). The physiotherapists perceived that for some patients it would take many years before their hopes shifted from having concrete hopes of a cure, to being hopeful of a good life.

7.3 Summary

In this chapter, I described the therapeutic employment of acceptance employed by the physiotherapists to manage hope and expectation in SCI rehabilitation. Furthermore I identified the therapeutic actions the physiotherapists drew upon to try and co-construct the narrative plot of acceptance in interactions with their patients. Following this plot, the physiotherapists sought to guide their patients through a moment of realisation (and hopelessness) whereby they came to their own conclusions about what they were realistically capable of achieving. A key feature of therapeutic employment therefore involved directing their patients away from the unrealistic concrete hopes embedded within the restitution narrative, towards realistic transcendent hopes offered by the quest narrative. In the next two chapters I turn attention to the experiences of activity-based rehabilitation (ABR) from people with SCI and their trainers. These chapters expand upon the issue of managing hope and expectation of SCI rehabilitation as I explore the PA messages promoted during ABR and how hopes and expectations of ABR are managed in this context.

**Chapter 8: Factors Impacting Participation in Activity-
Based Rehabilitation**

8.0 Overview

This chapter and the next chapter focus on the clients' and trainers' storied experiences of activity-based rehabilitation (ABR) and my observations at Neurokinex. In line with what Gubrium and Holstein (2009) refer to as analytical bracketing, this chapter focuses on the *content* of the stories to explore the impact of engaging in ABR on the lives of people with SCI. As Frank (2010) explains, the process of dialogical narrative analysis (DNA) first involves bracketing the storytelling scene to bring the content of the story into focus. Exploring the content of the stories is important within this thesis in order to answer questions regarding *what* is being said in the story (e.g. What were the barriers to exercise? What did people do to overcome these barriers? What facilitated continued engagement with ABR?). The next chapter turns the attention to the principle analytic concern of DNA and examines the *hows* of talk and the *work* that stories *do* to and for people (Frank, 2010). Together these two chapters explore not only the story told by clients, but the effects of telling these stories. This chapter builds upon the knowledge of the barriers, benefits and facilitators to leisure time physical activity (LTPA) for people with SCI identified in the meta-synthesis in chapter three. It therefore complements the meta-synthesis whilst also extending knowledge by identifying the factors that specifically impact participation in ABR. An analysis of the clients' stories revealed six narrative themes that impacted their participation in ABR. These were: the environment and culture of Neurokinex; family and healthcare professionals; health and well-being; body-self relationship and identity; pleasure; and sharing stories of ABR.

8.1 Environment and culture of Neurokinex

The results of the narrative analysis revealed that Neurokinex was a unique physical environment that enabled clients with varying levels of paralysis to be physically active. Moreover, it was also a unique "narrative environment" in that it offered clients a different story of LTPA and SCI than what they were exposed to in hospital. As Gubrium and Holstein (2009) propose, a narrative environment supports and values specific narratives while disregarding and silencing others. At Neurokinex, the narrative environment promoted by the centre was deeply rooted within their tagline of *redefining possibilities* following SCI. It invited certain stories and behaviours from clients that evoked the feeling that people were not defined by their current abilities. This is not to say that the centre and the trainers told stories of cure and recovery from SCI through exercise. Rather, the trainers provided the clients with the opportunity to try exercises that were off limits to them in formal

rehabilitation. As highlighted in chapters six and seven, physiotherapists focus their exercise routine with patients on maximising function. If they do not perceive that a certain exercise has any functional benefit (e.g. walking a patient with a complete SCI on the treadmill) then they will not entertain the idea of focusing on this activity. In the context of Neurokinex, the trainers were not restricted by the same time pressures that operate within formal rehabilitation. Therefore one of the reasons that attracted people to Neurokinex was the limitless attitude towards LTPA demonstrated by the trainers as they adapted exercises to make them as accessible as possible. As Lee described, this open-minded and limitless attitude of the trainers at Neurokinex facilitated his continued engagement in ABR:

And in Neurokinex they literally let you do any exercise you want to do, even if you think you couldn't do it you could ask them and they could find a way to try out. And if it doesn't work it doesn't work and you can try something else. But they make any sort of exercise feasible which is good because it stretches you out in a way that you can't do otherwise, you can't do it by yourself. I can stretch myself the way I feel after when I go to Neurokinex, as far as I know there is nowhere else to go to get like that (2nd Interview).

The narrative environment that the trainers operated within shifted the focus from avoiding activities the clients were not allowed to try in formal hospital rehabilitation, to opening up new types of LTPA to them. Many of the clients welcomed the new challenge that ABR provided them with as they were confronted with full body exercise routines that were starkly different to what they had been exposed to in formal rehabilitation. Allowing patients to make their own decisions regarding their rehabilitation in physical therapy gives them a perceived sense of control to partake in more desirable activities (Jordan et al., 2013). The perceived control over one's own rehabilitation in the community therefore facilitated long term participation in ABR.

A second welcomed difference between formal rehabilitation and ABR was the focused one-on-one training that the clients received at Neurokinex. In formal rehabilitation the physiotherapists would often be seeing multiple patients at a time during physical therapy sessions (see chapter six). Many clients felt that they did not receive enough attention from their physiotherapist and desired a more personal approach to their rehabilitation. This was something that Neurokinex could offer. Each client at Neurokinex had a dedicated trainer to work with them for the entire duration of their exercise session. At times, for certain exercises, there could be up to four trainers assisting one client. This was more common for

complex movements such as crawling and walking on the treadmill. The clients valued this personal approach not only for the exercises it allowed them to participate in, but also for the relationship they built with their trainers as highlighted by Oliver:

It's been six months now and it's been amazing, just totally amazing. The people here, the exercises, the exercises are brilliant but as I said it's the people as well. But yeah the relationship between the trainer and the person is very important I think. They are so knowledgeable... They push you so much, if you do these exercises yourself or whatever you can't get that extra push. But umm, no it's just, I didn't know it would be this good... just the whole like pushing, getting you to do more than I would probably do. I would have given up a long time ago if I was just doing the exercises by myself (1st interview).

As Oliver commented, the close relationship developed between the trainers and clients was both a benefit of ABR and a facilitator of continued participation. The trainers provided the motivation that was crucial to engage people with SCI in ABR over time. Furthermore, the trainers provided a source of informational social support as they were able to provide advice, suggestions and information (Cohen et al., 2000) to clients on many other aspects of living with SCI. Through keeping up to date with current research, and more importantly, through listening to the stories of others with SCI at Neurokinex, trainers were perceived by clients to be extremely knowledgeable. In other words, the trainers were valued by clients as *credible messengers* of information regarding SCI (Smith et al., 2015).

The third difference the clients made between hospital rehabilitation and ABR was the gym like culture operating within Neurokinex. In contrast to the perceived medicalised approach to exercise within the SCI centres, the trainers provided a more relaxed and supportive approach to LTPA at Neurokinex. In particular, many clients referred to the friendly teasing, or “banter”, between them and their trainer. This banter allowed people to laugh and joke in the face of adversity and meant that the gym floor was often a place where clients and trainers were constantly smiling and laughing. Indeed, light heartedness and laughter are important in keeping patients positive during rehabilitation (Soundy et al., 2014). The importance of this relationship to both the clients and their trainers was highlighted by Jemma (Trainer):

I think there's like a social aspect to the job as well, making it like fun and chatting to them, I like to be quite laid-back. Still get what I want to get in the session but also to have a laugh and stuff like that as well so it's not too serious. I think they need to be able to get on well with you and trust you and stuff like that, so you to then be able

to tell them you're going to do this and they are quite happy to do it because they feel like they know you quite well. Obviously there's an element of putting the exercises in place and doing them properly and safely. Also building that client trainer relationship well enough for them to want to keep coming back, and want to come to your sessions as well as seeing the physical changes as well.

Within the narrative environment of Neurokinex, stories were valued when the storyteller took on a positive outlook on life with SCI and was up for 'having a laugh' and 'a joke' on the gym floor. Due to the higher prevalence of traumatic SCI in men compared to women (World Health Organization, 2013b), the gym floor was a predominantly male occupied area. The typical storytelling in this environment was composed of masculine banter. This form of communication revolved around trainers and clients insulting each other, telling sexual jokes, and recounting stories of past dating escapades. These acts are part of the process by which men with SCI re-establish culturally normative masculine behaviour that aligns with their post injury identity (Gerschick and Miller, 1995; Jordan et al., 2013). However, there were drawbacks to this overly masculine gym environment:

Sarah: I would just say pull it back a little bit and try and introduce that sort of, softly, softly area and the opportunity at the beginning of each session just to say Sarah is there anything really, how's your week been, is it good? Don't get me wrong, the men are really gentle and lovely. But because you're trying to be so brave all the time and that's going to impact on the exercises if you're trying to be so brave that you, you know you can't just say something. But then again they might say we're not counselling, you know so I don't know (1st interview).

As Sarah's comments revealed, whilst the narrative environment at Neurokinex invites stories that fit within the redefining possibilities ethos it can silence stories regarding the more distressing aspects of living with SCI. That isn't to say that other people didn't talk about the difficulties in their lives. As mentioned earlier, the trainers were able to offer social support to their clients. However, in most instances, these conversations took place in the waiting area rather than on the gym floor. In this sense, there was a subtle difference between the masculine banter that circulated within the gym floor and the stories which circulated within the waiting area. Another reason for this difference may have been due to the divide between the gym floor and waiting area. Friends, family and carers were restricted to the waiting area and not allowed on the gym floor. This provided them with a space to share their own stories about living and caring for those with SCI and provided the clients the

opportunity to temporarily escape the seriousness of living with SCI. This aspect of escapism is explored further in the section on pleasure.

Critical reflections: Box 8.1 – Banter at Neurokinex

To effectively carry out this research at Neurokinex I have tried where possible to fit in to the narrative environment and integrate myself within the clients and trainers ways of interacting and communicating. As such, I have been the target of much banter and the butt of many jokes. Today was no exception as I was assisting with Thomas's training programme. Thomas is a typical lad and is constantly making jokes, teasing me, and coming out with sexual innuendoes. None of which I found offensive, he's just genuinely comical. Thomas agreed to be interviewed after the session today. He openly talked to me about his experiences in hospital, problems with being in the care home, the problems with returning to his house and how inaccessible it was, and I got the impression he doesn't normally talk about these kinds of issues. I certainly never heard him talk about anything related to his life outside of the centre whilst he's exercising.

Thomas' composure during the interview totally changed. Gone was the comical lad, instead I was privileged to listen to some of Thomas' most heart wrenching moments following his SCI. I actually had a tear in my eye when I transcribed his interview, because using Dragon means I have to speak those words. And they are hard to listen to, let alone say out loud. It made me realise that I have no idea what these people are going through in their everyday lives. I think that my willingness to participate in the narrative environment through friendly banter is an important part of the research process. In my fluid role as complete observer to participant as observer (Sparkes & Smith, 2014), I have shown that I am comfortable with this environment by assisting with exercises and being capable of partaking in banter. Accordingly, I believe my acceptance at Neurokinex has resulted in clients sharing their stories with me as openly as they have. I was just shocked in this instance at the stark difference between Thomas' stories on the gym floor and those he graciously shared with me in private.

8.2 Family and healthcare professionals

There were other characters in the clients' stories, aside from the trainers, who played a significant role in enabling or preventing a physically active lifestyle at Neurokinex. These were family, friends and healthcare professionals (HCPs). In particular, friends and family were instrumental in assisting people overcome the barriers to attend Neurokinex. They played an important role in providing instrumental social support. Instrumental social support involves providing tangible aid and service (Cohen et al., 2000) and in this case included raising the money to cover the cost of individual ABR sessions, providing or arranging transport and rearranging certain aspects of their daily lives to accompany the clients to the centre. For some, this included leaving the family home for days at a time and staying at a local hotel to facilitate regular attendance. As with other alternative therapies (Petersen et al., 2013), these family members were as heavily invested into Neurokinex as the clients were. Most notably however, it was predominantly clients' family members who first introduced them to Neurokinex. This was demonstrated by George as he describes the instrumental role his mum took in finding him LTPA opportunities following his SCI:

I think mum took it upon herself on the day I had the bump and they knew I had a spinal cord injury. So by the time I woke up out of the coma there was already information and plans and places I could go to and so on. We said we would try this for at least six months and see how it goes... I know without the support networks that you have with your parents, family and friends, I probably wouldn't be up here now if it was all down to myself trying to research and find things out. It wouldn't, it would I don't think it would have worked as well if I didn't have someone pushing, and trying to find different things for me to do (1st interview).

As George explained, the informational, instrumental and emotional social support from his family and friends served to motivate him to initially participate in ABR and was essential to facilitate his continued engagement in the programme. In this sense, the clients' stories of ABR were co-constructed by family and friends (Crossley, 2011; Frank, 2013) as they shaped their thoughts and feelings prior to entering the centre. For George, the continued support from his family persisted to shape his experiences at Neurokinex. This co-construction of experience was evident as he referred to the joint decision making process with his family to continue ABR. He often said "we" made the decision, rather than "I", signalling the importance of his family in making this decision.

Although family and friends promoted and facilitated a physically active lifestyle for the clients, this was not perceived to be the case with their HCPs (e.g. doctors, physiotherapists, nurses). Most of the clients were advised to remain physically active, and at the very least to stand for an hour each day. However, no-one was directed to any specific LTPA opportunities upon discharge from the SCI centre. The few clients who tried to discuss ABR centres with their HCPs in the SCI centres received varying negative responses. These negative responses were reported as a lack of co-operation in assisting with the pre-requisite health checks, warnings to be cautious of these centres in building up expectations, and advice not to attend. These findings are in tune with the physiotherapists' views presented in chapters six and seven, and provide a consistent picture of the lack of communication between HCPs and community-based ABR centres. This perceived lack of willingness to consider ABR as a viable LTPA opportunity for people with SCI was a source of frustration for the clients. Many were of the opinion that HCPs should encourage people to try all LTPA opportunities, rather than not acknowledging they exist:

George: I think they can improve a lot of things they do. And trying instead of becoming one way in a negative way about what you can and can't do. You can encourage people to go out there to try everything, and if they want to try it don't try putting them off or telling them "well we didn't think you were going to be able to do that." Say, "go and give it a go, why not, what have you got to lose. You're not going to injure yourself any different, as long as you don't put yourself in harm's way." Then go and try it, why is anything going to stop you trying something. I can understand why they couldn't tell everyone there is this place go and try and do that it might help you. And then if it doesn't help then obviously people could become more depressed, or worse. But then maybe it's my mentality, I would rather someone say here is a list of different places that could help go and try them. Because to me if I don't try, then I would probably be more depressed not trying it, rather than trying it and at least I know I've tried to do something (2nd interview).

Through their unwillingness to consider ABR as a viable LTPA opportunity, HCPs are in effect acting as a barrier to enabling a physically active lifestyle. George's sentiments mirror findings from Petersen et al. (2013) who found that HCPs in neurological rehabilitation were perceived to offer limited or no treatment options post discharge. In turn, this further motivated people to explore alternative treatment options (Petersen et al., 2013). Similarly in this study, the lack of willingness to discuss ABR did not prevent or deter any of the clients, but increased their determination to try ABR. Furthermore, clients then chose not to share their stories of ABR with their HCPs during routine check-ups post discharge or

readmission to the SCI centre. This lack of communication serves to silence stories that would provide first hand experiences that could help HCPs shape their opinions of ABR.

8.3 Health and well-being

All of the clients' stories revealed perceived improvements in their physical and mental health and well-being as a result from engaging in ABR. The physical health benefits included an increase in strength and mobility, feeling less fatigued, weight loss and improvements in balance. In addition, participating in ABR provided benefits specific to SCI populations such as reducing the amount/severity of spasms, improved bladder and bowel routine and a reduction in pain (Martin Ginis et al., 2012; Tomasone et al., 2013). The specialist equipment and individually designed exercise programmes at Neurokinex are designed to benefit clients across all levels of SCI. For example, clients with complete injuries reported how the functional electrical stimulation (FES) stopped muscle wastage and how carrying out many of the exercises upright reduced dizziness when standing. On the other hand, for clients with incomplete injuries who were able to ambulate, the specialist equipment (such as an inbuilt track system with a harness) was considered invaluable for help with gait training and improving walking ability. As Oliver explained:

Yeah it's been good, really good. Still here (1 year later). Basically we've been doing the harness work on the track system and I think we started that last year sometime. I was using sticks before and recently I've been doing it without holding on to anything sort of thing. No sticks and even I've been bringing the left leg through as well, really, really good. Before Jemma (trainer) would be on the chair pulling it through. I can do one length without her pulling it through so it's really good. That's been one of the biggest improvements I've made in terms of my walking (2nd interview).

As well as improvements in physical health, all clients referred to the importance of ABR for their mental health and well-being. For some clients, regularly attending ABR was important in maintaining their mental health as they perceived themselves to be in a good place mentally before attending Neurokinex. Other clients' stories however told of perceived improvements in mental health from ABR that facilitated their continued engagement with the programme. These improvements were mostly concerned with aspects of subjective well-being (SWB) but also eluded to enhanced psychological well-being (PWB) (Ryan and Deci, 2001). In terms of SWB, clients associated general positive emotions from their participation in ABR.

George: I think you feel mentally better because you're doing things, you're actively doing things and you're not actually sat in a chair all day. You're up, you're standing, and you're doing different things every day. I think for your mental well-being it helps a lot as well (1st interview).

This was also reflected in the trainers' perceptions of the benefits their clients received from partaking in ABR:

Louise (Trainer): I massively see them happier, you always see people get more confident and get happier and really get into things. Even someone like Richard who doesn't seem very extrovert at all, when he first came here I remember him he was high on drugs, medication (laughter). It just zonked him out, he just wasn't with it, he just didn't want to talk to anyone, he was closed down sort of thing and it was quite sad. He was probably the most not with it and completely disconnected with his body person that I've probably seen. Then you see him now, he chats to everyone, he's coming out with cheeky comments all the time, you see him smiling. I know it's not much compared to somebody who is very happy and outgoing, but for him I can massively see that change.

Furthermore, improvements in physical mobility and capability increased life satisfaction by making activities of daily living easier and less of a struggle. Participating in ABR also enhanced PWB as making the effort to travel to Neurokinex and exercising for several hours gave some clients a sense of purpose in life. This was of particular importance for people with higher level injuries and a subsequent increase of paralysis. This was illustrated in the following comment from Thomas:

I was pretty much down the scale where I couldn't really go no worse you know. I couldn't really move at all so everything for me that I can do now, lifting a cup up, and stuff, using a mechanical arm to eat with and bits and pieces is a bonus. Also mentally as well I find it, I find that I've come away I've done something, I strive to do something and it keeps my brain working on a positive note because it's very easy to go negative and go down that road (1st interview).

For many clients, it was the combination of physical and mental benefits from ABR that was of great importance to them. As Thomas' story highlighted, the smallest improvements in physical capability enhanced his SWB as he was able to feed himself and increase his independence. Thomas' story additionally reveals how SWB and PWB can influence each other. This is evidenced through his description of how having a purpose in life from attending ABR was important to maintain positive emotions following SCI. In addition, participating in ABR boosted clients' social well-being (WB) (Keyes, 1998) as it

gave people the opportunity to integrate with peers with SCI. Indeed, peers with SCI are a great source of support in terms of listening, encouraging and providing information (Soundy et al., 2014; Smith et al., 2015). Being in this environment with peers both on and off the gym floor, provided a much needed source of emotional and informational social support, especially to those clients who were otherwise socially isolated in their everyday lives. These findings regarding Neurokinex are in tune with the results from the meta-synthesis (chapter three) that perceived health and well-being benefits obtained through LTPA as a major benefit of, and facilitator to, long-term LTPA participation.

8.4 Body-self relationship and identity

The intense and physically demanding exercise routine of ABR provided additional benefits to clients in terms of their body-self relationship and identity. Firstly, partaking in full body movements, including exercising paralysed body parts, provided the opportunity for clients to feel more comfortable in their body, improving their SWB, and to consequently re-establish and re-integrate their body-self relationship (Jordan et al., 2013). This is evidenced in the following quote from Sarah:

Sarah: Firstly I think just being, feeling that you haven't got tight muscles, feeling much more comfortable in your own body and also not feeling so lethargic, feeling like you've got a bit more energy.

Interviewer: when you say more comfortable in your own body what do you mean?

Sarah: I think it's a lot of things really, I think it is appearance because you know when you're sitting well and your skin is glowing you're feeling good, that's a real appearance thing. I think also trying to sort of reconnect and keep in touch with your body when you feel disconnected from your body due to a spinal injury.

Secondly, participating in intense LTPA benefitted clients as they were able to redefine their physically active identity following their SCI and realign the body and the self. Whether or not clients were involved in sport and exercise before their accident, all of them now perceived the importance of staying physically active following their SCI (see chapter nine). Interestingly, although some clients engaged in other forms of LTPA outside of Neurokinex, they chose ABR over disability sport. There were various reasons as to why ABR was the preferred choice of LTPA. For example, for one client, the whole experience of attending Neurokinex replicated and replaced his previous LTPA experiences:

George: it's very different because obviously I've lost, I haven't lost all that, but the aspects of going out with my mates, going to the gym, playing football, all that's gone. But obviously that's why I come to Neurokinex because it keeps you mentally healthy as well. Because you are actually working out every day, and being physical as much as you possibly can all day. In a sense yeah you've lost it, but then you've also gained it in a different way as well, so it's okay (2nd interview).

As George commented, participating in ABR has enabled him to regain his physically active identity he had previously embodied before his injury. The high intensity workout that ABR provided replicated the level of LTPA that George was able to obtain through gym workouts and playing sport before injury. He has therefore lost the physically active identity that was embodied through *independent exercise* and *team sport*, and gained a physically active identity comprising *high intensity assisted exercise*. Therefore for some clients, Neurokinex provided a space to negotiate the possibilities for new selves, as well as maintain core identities through participation in ABR (Levins et al., 2004; Stephens et al., 2012; Jordan et al., 2013). Other clients chose ABR over other LTPA opportunities because of the opportunity it provided for them to exercise independently of their wheelchair. In this instance they predominantly rejected wheelchair adapted sports in favour of other exercises such as swimming as well as ABR. Engaging in these LTPA opportunities allowed some people to develop and embody a new PA identity, but also highlighted their rejection of any disabled identity. One example of this rejection of disabled identity occurred during a conversation with Daniel during which the following field note was recorded:

I joined Daniel and Matthew whilst they were exercising on one of the total body workout machines. They were discussing the Paralympics and disability sport in general. Daniel commented on the fact that Paralympians were not real athletes, and the Paralympics were not the real Olympics. This sentiment was echoed by Matthew who also said that Paralympians are not real athletes because there are less people able to compete alongside them, therefore they're only good because of their impairment. When we spoke about doing wheelchair sports Daniel was adamant that he didn't want to do any kind of disability sport. I know he's spoken about doing a triathlon before, but this would be alongside able-bodied competitors. After our conversations about socialising with others in a wheelchair, I get the impression that Daniel doesn't want to be associated with other disabled people. I don't think he sees himself as 'one of them' as he puts it (November 2013).

8.5 Pleasure

A new finding that emerged in this study, that was absent from the meta-synthesis on barriers, benefits and facilitators of LTPA, was that of the pleasure of exercise. As Phoenix and Orr (2014) point out, pleasure is the forgotten dimension of LTPA as much of the research on health behaviour overlooks how the act of pleasure might *contribute* to health. All of the clients' stories referred to some form of pleasure from exercising at Neurokinex. For many, the pleasure they experienced related to the sensory dimension of ABR and in particular the embodied experiences of exercising their partially paralysed bodies. *Sensual pleasure* can be defined by the senses, mainly touch and feel, connecting people to the experience of pleasure during exercise (Phoenix & Orr, 2014). For example, Stuart exemplified sensual pleasure as he recounted the sheer enjoyment from participating in ABR and the gratification of feeling exhausted after exercising:

Well, after each, to start off with, after each session I feel good, just makes you feel good. You're tired but it's just like, literally like you've been for a run, there's nothing else, it's very, very hard for me to get that feeling now. That feel good just after you finish is a massive part of it... but, again whenever we arrive at Neurokinex there is no sitting around, as soon as you arrive there you're gone and you do your two hours of whatever it may be, torture basically... The way it makes you feel, that tiredness, that out of breath feeling, that's not something you get all the time after this happens to you. I love it, I really enjoy it, I find it really addictive (1st interview).

As Stuart's comments illustrated, ABR was the only vehicle that replicated the embodied feelings and sensual pleasure (and *displeasure* in the form of "torture") of an intense physical workout. This sensual pleasure had a positive impact on Stuart's SWB and facilitated his continued engagement with ABR. Likewise, Thomas' comments echoed those of Stuart, and others, as he recounted the pleasure of being physically handled by the trainers at Neurokinex:

I didn't just want to sit at home and use pulleys and stuff like that which I've been using. I quite like the idea of being put on the bench and being manhandled really (*laughte*). Pulled about arms legs and everything, and feeling like that someone was actually trying to do something for me rather than me trying to do something for myself all the time. I come away like sitting down my arms are aching, I ache. It's a nice feeling just to be aching, just to feel like you are aching because your arms and stuff that you thought wouldn't hurt. Even my stomach, I can feel my stomach muscles pounding away a little bit which I really shouldn't be but it's great (1st interview).

Thomas's comment indicates the intimate connection between his sensual body and the surrounding environment (Coveney & Bunton, 2003; Phoenix & Orr, 2014). In this instance, the surrounding environment included the physicality of the exercise machines and other bodies including the trainers and assistants at Neurokinex. With high level tetraplegia, Thomas is unable to do any more than feed himself and is therefore reliant on the machines and other bodies to move his paralysed body. The sensual pleasures obtained from participating in full body workouts at Neurokinex were exemplified by his paralysed body and his inability to control his own body and recreate the aching sensation from physical exercise independently. Thomas, like many other clients, also referred to the pleasure of sensing "that aching feeling" after exercise in areas of his body where he otherwise has no sensation. As well as experiencing sensual pleasure as instant gratification, Thomas implied that the aching lasts beyond the duration of his exercise session. This is an example of how pleasure is bounded by the time, place and space in which the exercise took place, but also how the feeling of pleasure can *expand* into the immediate aftermath of the activity (Phoenix & Orr, 2014).

Another example of how sensual pleasure illustrated the connection between the sensual body and surrounding environment was provided by Sarah. In her descriptions of participating in ABR, Sarah likened the intimacy of many of the exercises to that of dance and gymnastics:

Sarah: it's a bit like having a dance partner I think. When I did gymnastics I had a gymnastics partner because we did pairs gymnastics. This is where you hold each other as you lift each other up. So doing some of the lifts and holding it just feels like an extension of that really.

Interviewer: and is that relationship important to you?

Sarah: yes I think it's really important because I think you end up having some understanding of each other's, not emotions but like if they realise that you know you're having a bit of a bad day they sort of quickly tune into that. And sometimes when you're in the middle of an exercise and something a bit difficult, or bit off-balance, you can just communicate that almost without words. I kind of just am very thankful really for what they do and very respectful of, because it is very physical and it looks very intimate at times. But it's not, it's just what you're doing.... I think as well another thing about it is that I see so many crossovers with dance... because you're trying to move your body you're trying to do something with a disabled body that you weren't born with and it's emotional (1st interview).

Adding a further dimension to the embodied sensual pleasure of exercise with SCI, Sarah's comments illuminated the importance that this intimate action had on the relationship with her trainer. Through connecting her sensual body to that of her trainer's, Sarah was able to build a deep relationship – a dyadic rather than monadic relationship – between them whereby she could communicate without words. For Sarah, this connection was emotional as she compared the intimate exercise at Neurokinex to that of dance and gymnastics. In this sense, sensual pleasure was experienced not only in the moment, but through her ability to associate this activity with a pleasurable experience of the past.

As mentioned above, all of the stories of pleasure acquired from ABR included some aspect of sensual pleasure from exercise. However, other types of pleasure were also evident in the clients' stories. For example, some of the clients' expressed pleasure from immersing themselves within their exercise at Neurokinex. In this sense, pleasure is experienced from the focus and immersion in an activity that allows people to escape from everyday issues in their lives. Furthermore, as Phoenix and Orr (2014) explain, through the process of *detachment* from everyday issues, *pleasure through immersion* can also be achieved through *attachment* to another place. In this context, some clients were able to experience a certain type of pleasure at Neurokinex as ABR redirected their focus away from the daily struggle of living with SCI. In addition, the enabling, accessible, supportive environment of Neurokinex provided other clients with a sense of pleasure from regularly immersing themselves within this environment. George exemplified this as he described the pleasure he experienced from regularly spending his weekdays at Neurokinex:

You get a better vibe when you come in here, I go home on a weekend every weekend and I can't wait to come back on Monday. Because the vibe is good here, and everyone gets on well, you can have a laugh and a joke with the physios and like I said the music is on. It feels like a proper gym, but it's just you need that little bit of assistance and some of the stuff you are doing you wouldn't see on a regular gym. But it does feel like a proper gym, and it doesn't feel like a chore to come here it feels like you want to come because of the enjoyment you get out of it, as much as what benefits you get out of it as well (1st interview).

George's comment draws attention to the important role pleasure through immersion in activity played in improving his sense of well-being. As with sensual pleasure, the pleasure of immersion was most intense *during* the activity of exercising (Phoenix & Orr, 2014). That said, as George's comment suggests, the pleasure of immersion in Neurokinex has the potential to extend beyond his exercise sessions as the excitement of coming back on a

Monday builds over the weekend. As well as experiencing pleasure through immersion at Neurokinex, George, like others, also expressed a form of *habitual pleasure*. This refers to the routine of regular exercise that provided a sense of structure to his life (Phoenix & Orr, 2014). As Phoenix and Orr (2014) note, the pleasure gained from habitual action is especially important for older adults in the aftermath of life changing events such as retirement. SCI is also a life changing event whereby clients can find the expanse of “un-allocated time” overwhelming (Phoenix & Orr, 2014, p.98). In this context, the routinised behaviour of regularly attending Neurokinex (every day, or once a week) provided clients with a sense of constructive use of their expansive free time. This important component of habitual pleasure was illustrated when Lee described his regular involvement in ABR:

Yeah just like you know, you feel happier and when I leave here my endorphin levels are crazy, I'm on a high. Otherwise during the week I feel better as well like, and knowing that, because I wasn't really doing anything constructive as well with my time. So this is like a good two-hour constructive thing that I'm doing every week, that's fixed as I'm not working or anything at the moment I was so just wasting time watching TV and everything. So I find this something useful I'm doing as well, you know (1st interview).

In addition, as Lee's comments suggested, the pleasure gained from habitual exercise had the potential to expand into the time in between sessions at Neurokinex. That is, while sensual pleasure facilitated feelings of instant gratification, habitual pleasure could be encountered *after* the activity had taken place. Thus, whilst sensual pleasure was primarily encountered in the *present*, the pleasure of habitual action enabled clients to connect previous episodes of exercise and experience habitual pleasure *from the past into the present* (Phoenix & Orr, 2014).

Another type of pleasure that was inductively identified in this study was *documented pleasure*. Documented pleasure occurs through the process and outcome of documenting one's activities (through archives, manuals and diaries etc.) which becomes a pleasurable act (Coveney & Bunton, 2003; Phoenix & Orr, 2014). In some instances, clients' stories included aspects of documented pleasure as they discussed their physical progress by monitoring improvements in strength and fitness through their rigorous training routine both within and outside of Neurokinex. For example, Daniel demonstrated documented pleasure as he talked about reducing the time for his one mile swim, the importance of keeping his heart rate consistent (measured and documented through wearing a heart rate monitor), monitoring his

body weight and keeping a record of his weekly weight training. This documented pleasure was encountered *after* the moment of doing the activity and, like habitual pleasure, had the potential to *extend* the pleasure of the activity and expand the experience beyond the space where it took place (e.g. swimming pool, gym) (Phoenix & Orr, 2014). Whilst on the one hand the act of documenting physical progress could be a source of pleasure, on the other hand, in the case of LTPA and SCI, measuring physical ability could also be a source of *displeasure*. This component of documented displeasure was evident in the following field note taken during a six month assessment with Richard:

Today I witnessed my first ever evaluation. This evaluation is a test of people's functional scale and motor score that is performed every 6 months. Chris was incorporating Richard's evaluation into his normal session and I was acting as assistant, fetching equipment and assisting with transfers etc. as normal. What was most striking about this interaction was Richard's total lack of engagement in the process. Chris started with Richard's legs and went through the motions of asking him to move his toes, ankles, and knees, even though both of them knew Richard could not perform any of these movements. From a lying position, Chris then proceeded to take one leg at a time and place it in the middle of his chest. He then asked Richard to try and push against his chest whilst Chris resisted his efforts. In addition Chris asked Richard to think about performing this action. Again no movement. No movement meant no progress in functional recovery. This continued for another half hour with Richard being asked to perform a range of movements on command, testing his core and upper body strength. All the while Richard said nothing. He just silently complied with the evaluation (September 2014).

As suggested in the above comments, the six month assessment of progress could be a source of displeasure when no progress is made. This displeasure could arise from the ability of documented pleasure to connect individuals with *other* bodies (Phoenix & Orr, 2014). These other bodies can include one's former body or future body, and the bodies of others. In Richard's case, this assessment was a source of displeasure as it was a stark reminder of his former able-bodied self and his present and future disabled self.

A fifth type of pleasure that was identified in this data was the *pleasure of "normative" activity*. In this instance "normative" activities referred to standing, walking and cycling, many of which the clients could no longer carry out independently post-injury. The pleasure from being able to carry out normative activities following SCI is demonstrated in the following description from George:

I really enjoy the walking aspect of it. I don't know why, I don't know if it's because you are up straight and walking. I could do that all day, I really enjoy it. I don't get tired, it's hard work but because you enjoy it I think you do it more. And the spin bike as well because I'm able to do that on my own without any helpers. I can just peddle away and do that for 20-25 minutes easy. I think with the spin bike and the walking it's like a normal thing you would do day-to-day. I don't get to do walking at all at home, so when I'm up here and I get half hour, 45 minutes of walking it's like a natural thing, a more real thing and it brings you back to what it was like before. I think that has a big thing to do with it, because it is more real to you, I think that is why it is more enjoyable (2nd interview).

Physical therapy programmes that involve aspects of walking have been identified as representative of both normative and desirable activities for people with SCI (Jordan et al., 2013). Furthermore, they are associated with a *momentary return* to one's former body (Semerjian et al., 2005). George's comments, echoing many of the other clients, suggested that the pleasure of "normative" activity also has the ability to connect individuals to other bodies. Through assisted walking, George was able to connect to his former able-body. Jordan et al. (2013, p.1036) suggested that physical therapies that include walking, such as locomotor training (LT), allow clients to "revel in the feeling of inhabiting an upright body", a feeling that some people may not have had for years. However, other therapies such as LT are quite different to ABR. Firstly, LT relies on robotically assisting clients to walk on a treadmill whilst supporting their body-weight. Secondly, it is only provided to patients with incomplete SCI to improve their ability to walk independently (Jordan et al., 2013). Complete patients like George would therefore be denied the pleasure of "normative" activity if it were not for other LTPA opportunities such as ABR.

8.6 Sharing stories

As stated earlier, peers are a great source of support in terms of listening, encouraging and providing information to others with SCI (Soundy et al., 2014). The act of storytelling is one way in which people with SCI share information regarding their experiences of LTPA (Smith et al., 2015). However, most of the clients perceived themselves to be in a 'fortunate position' and were very aware of people with SCI to whom Neurokinex would be inaccessible for economic reasons. With this in mind, many clients stated that they would not recommend Neurokinex to others with SCI unless they were sure they had the means to pay for it. In this instance, the high cost of regularly exercising prevented people with SCI from sharing stories

of their experiences of ABR with their peers. This concern was exemplified in the following extract from Daniel:

Daniel: I don't know it's difficult, it is really difficult. You've got to be careful with, because it's just the funding. Someone could really want to come and someone could really want to do this, but if they ain't got no financial backing behind them it's not possible. And I don't think it will, I don't know, I just can't see, the NHS can't afford things as it is. There's no way that they're going to be sending people here for the amount of money that it is, I think. I don't know, I'm just very fortunate that I've come from a family that can afford to do this.

Interviewer: That would be your biggest worry, encouraging someone and then them not being able to afford it?

Daniel: Yeah, I think I would have to, you'd have to know who you were talking to before you know. If they've had like a 5 million pound pay out then yeah, all for it. But you know, I wouldn't want to say to someone do it, do it, and then you realise that they can't afford it. You know you've built their hopes up. It is hard to sort of, I don't know what I would do really if I couldn't afford it (1st interview).

As Daniel's comments illustrated, his reluctance to share stories of ABR were ultimately related to managing hope following SCI. As he insinuates, he wouldn't want to build up someone's hope of participating in ABR and continuing their rehabilitation if they did not have the resources to attend. This comment was echoed by the trainers. They were very aware that the high cost prevented many people with SCI from partaking in a therapy that could be of huge benefit to them:

Chris (Trainer): Obviously I think money is a massive part of it, I think often there are thousands of people who just can't afford what we do. Let's be honest I couldn't afford to come it's so expensive. It would be so nice if we can get on some kind of scheme where they will not have to pay so much. Because there are probably thousands of people sitting at home not being able to do something.

The second barrier to sharing stories with peers was concerned with the type of exercise promoted through ABR and its suitability for different severities of SCI. As stated on the website, ABR aims to "stimulate the body to work as one unit again and if possible to re-establish some form of a link or pathway between the paralysed and functioning parts" (Neurokinex, 2014). In effect, therapies such as ABR are trying to capitalise on the neuroplasticity of the central nervous system to enhance functional recovery of the spinal cord through repetitive high-intensity exercise (Jordan et al., 2013). At Neurokinex, clients

are further encouraged to *think* about moving their paralysed body parts in an effort to re-establish a neurological pathway around the site of damage on the spinal cord. This was illustrated in the above field note from Richard's six month EVAL. However, physical therapies that try and enhance neuroplasticity are preoccupied with patients that have an incomplete injury and therefore some movement or sensation below the level of injury (Jordan et al., 2013). There is as yet, no conclusive evidence to suggest a completely severed spinal cord (with no movement or sensation below the level of injury) can recover. With this in mind, some clients had concerns over the suitability of ABR for peers with complete injuries:

Steve: I wouldn't necessarily recommend Neurokinex to everybody because there was a lot of focus about working on your core and if you haven't got a core I don't know where they go after that. And there were a lot of things I just couldn't do, it was like "right really try this, really try this." And I know, I know I've been like this for four years I know that my stomach doesn't work, my legs don't work, I know that. So yeah, some of the exercises I think some people would think pointless. So yeah not necessarily everyone.

Interviewer: is that because you don't see a benefit in exercising below the level of injury?

Steve: umm, it was just a lot of it about "now picture your leg moving, move your leg you know" and I know my leg doesn't move. That's not me being lazy (*laughter from both*) I know it doesn't move. You know so it's like that and that's my one reservation about how long I would go for because of this trial week and a big part of it was that long-term I know that would be useless for me. So it's a case of how much other stuff I can do (1st interview).

Steve's comments suggested that he didn't "buy in" to the story of reconnecting with his paralysed body through ABR (Frank, 2010). Furthermore, Steve found this notion of being asked to move his paralysed body frustrating, and more importantly, a source of displeasure. For this reason, Steve had reservations about his continued participation in ABR and the likelihood of him promoting Neurokinex to other peers with complete injuries.

The third barrier to sharing stories of ABR with peers related to the time since injury occurred. The common belief among staff and clients at Neurokinex was that the sooner people started exercising after their SCI, the better chance they had of any functional recovery. This notion is linked to the two year window post injury that has been suggested by studies in SCI recovery to be the time in which functional recovery is most likely to happen

(McDonald et al., 2002; Harkema et al., 2012). However, in line with research into PA messages, some clients perceived that not everyone would be ready to hear messages surrounding PA immediately following discharge from rehabilitation into the community (Letts et al., 2011). SCI is such a traumatic injury that people are often more concerned with dealing with other aspects of their new life before they are ready to consider being physically active (Kehn & Kroll, 2009). For Sarah however, her concerns were linked to identifying people as “disabled”:

No I can't say that I would (promote Neurokinex) because for some people it might be painful. I mean if I had gone when I was newly injured I think I would have found it quite painful still seeing other wheelchair users around... I think you don't, it's a bit like oh you're in that group now, you're a disabled person, you belong to that group. Rather than saying oh you wear, you wear glasses so you're in the glasses users group. You know being a disabled person is such a broad spectrum, people think that they're lumped into some group that they don't want to belong to or they didn't choose to belong to. And so they feel defined by that but obviously you're not defined by your disability. But post-injury that's all you can think about and so you've learnt to define your new body by its injury rather than elements of your character that you might not have discovered. Like well actually you've got an amazing sense of humour but no one told you that, and so I think for some people it's traumatic and they don't necessarily want to do that. And I know I was like that. (2nd interview).

As Sarah's comments indicated, she would be hesitant in recommending a specialist SCI exercise centre to a peer for fear of defining that person by their disability. Sarah further implies that she herself had difficulty coming to terms with her newly disabled identity and found it painful to be around other wheelchair users. Sarah's comments concur with research that suggests observing others with SCI does not always result in a positive effect (Dibb et al., 2013). As Dibb et al. (2013) noted, social comparison can be a negative experience for people when others are too similar and serve as a reminder of the current situation. In this case people use avoidance coping whereby they avoid meeting people who remind them of themselves. Sarah's concerns were allied to recommending ABR to someone who had not come to terms with, or *accepted*, their SCI (see chapters seven and nine). As this section shows, many of the barriers to sharing stories of ABR were in line with the concerns raised by the physiotherapists. These concerns were regarding managing hopes and expectations following SCI and acceptance of this life changing injury.

8.7 Summary

This chapter adds some nuances and depth to the meta-synthesis in chapter three by highlighting the specific factors that impact participation in ABR. For example, in this chapter I have highlighted Neurokinex as a unique environment and culture, both physically and narratively, that exposed clients to different stories regarding LTPA and SCI. The clients' stories told of the invaluable support provided by family and friends to facilitate a physically active lifestyle. This was in stark contrast to the negative responses clients received from their HCPs in considering Neurokinex as a viable LTPA opportunity post discharge. ABR was however able to offer clients many benefits to health and well-being and provided clients with a vehicle to re-establish their body-self relationship and identity following SCI; for some at the expense of their identity as a disabled person.

This chapter also advances knowledge of LTPA and SCI by identifying how people can benefit from the multidimensional pleasures of exercise. In this regard, pleasure could be experienced as different types and encountered in some instances beyond the physical boundaries of Neurokinex. This facilitated an ongoing commitment to engaging in ABR. Despite these benefits, there were multiple barriers that acted to prevent clients sharing their stories of ABR with their peers. Interestingly, their main concerns echoed those of the physiotherapists in chapters six and seven as they revolved around managing hope and expectation of ABR. The next chapter further explores the narrative environment of Neurokinex by identifying the dominant narratives that clients draw upon to tell their experiences of ABR and what type of hope is prevalent in these narrative types. In addition, the next chapter explores how the trainers tried to manage their hopes and expectations in this context.

Chapter 9: Typologies of Activity-Based Rehabilitation

9.0 Overview

In the previous chapter, through analytic bracketing, the storytelling scene was bracketed, and attention was focused on the content of the clients' stories. In this chapter, the content is bracketed, and the dialogical narrative analysis is expanded to "bring the storytelling back into the analysis" (Frank, 2010, p.105). The chapter examines the *hows* of talk and identifies the types of narratives that were drawn upon to scaffold and structure the stories of activity-based rehabilitation (ABR), and the *work* that these stories *do* to and for people (Frank, 2010; Sparkes & Smith, 2014). Individuals with spinal cord injury (SCI) drew upon three overarching narrative types in their stories of ABR. These were: 1) exercise is restitution; 2) exercise is medicine; and 3) exercise is undefined possibilities. These narrative types provide new knowledge as to how people with SCI understand their leisure time physical activity (LTPA) experiences in ABR. As Frank (2010, p.119) explains "A typology of *narratives* recognises that experience follows from the availability of narrative resources, and people's immense creativity is in using these resources to fabricate their stories. The types in a typology are of *narratives*, not people." Therefore it is important to acknowledge that although each narrative typology is supported with data from client quotes, no actual story conforms exclusively to only one typology. No individual can be reduced to a single narrative type. Rather, people operate within these typologies which act as resources for telling stories and expectations when listening to stories (Frank, 2012; Phoenix & Orr, 2014). Each narrative typology will be considered in turn by focusing upon the underlying plot, the consequence of telling these stories and how hopes and expectations are created and managed in this context.

9.1 Exercise is restitution

The restitution narrative is a dominant medical storyline that projects hope for recovery or cure after illness or injury (Frank, 2013). In SCI, the restitution narrative follows the plot of "yesterday I was able-bodied, today I'm disabled, but tomorrow I'll be able-bodied again" (Smith & Sparkes, 2005, p. 1096). The *exercise is restitution* narrative provides a new adaptation to this narrative type by specifically prescribing exercise through ABR, rather than medical interventions or technology, as the means by which a person can return to their former able-bodied self. This new narrative therefore reads: "yesterday I was able-bodied, today I'm disabled, but tomorrow through exercise, I'll be able-bodied again". Clients whose stories were shaped by this narrative structure were motivated to engage in ABR through a desire for restoration following their SCI:

Sarah: I definitely wanted the opportunity to do exercises which would test whether or not I had any movement below what I perceive to be my injury level and what that movement was. So for example, I'd always been told that I'd got biceps and wrist action, but since having gone to Neurokinex I have now discovered that I've got some core muscles that I'm able to use... I am really amazed at how much, not only movement and core strength I've gained, but also sensory sensations where in my legs and in my lower back and sort of bum muscles I can feel what felt like early feelings I had in my core muscles when I was doing exercise. Like slight tremors and tension building. So yeah, it's actually very exciting for me. I'm just taking it, and being very open minded, but I am quite pleasantly surprised... Even though I've questioned it over and over again there's a part of me that just thinks I will walk again. I just still, I just believe that I will (1st interview).

Sarah constructs a story of ABR whereby functional and sensory improvement is *emplotted* as a direct consequence of this intensive exercise programme. Through continued functional and sensory improvement, Sarah became “caught up” (Frank, 2010, p.48) in the story of restitution. In other words, the *exercise is restitution* narrative was reinforced through the restoration Sarah experienced whilst participating in ABR. Sarah was therefore able to construct a future narrative where she envisioned a restored self and body (Charmaz, 1987; Frank, 2013) and walking again. For others, functional restoration did not have to be forthcoming for them to tell a story of restitution. The following words from Daniel illustrate how the *exercise is restitution* narrative can interpellate (i.e. hail) (Frank, 2010) people to participate in ABR due to the restorative focus of the exercise programmes:

Interviewer: do you have any specific goals that you have in mind from coming here?

Daniel: Get back, get back to how I was. Yeah, get walking. We were looking at different ways to go. One was stem cell and then the other was like naturally, you know trying to get functionality back and that's why we chose this one... I just see how it goes. I know I'm progressing, getting fitter on everything just as a whole you know each week looking at different things. I haven't seen no massive improvement, do you know like, no like all of a sudden my foot started moving, do you know like being able to control my foot and stuff. Umm, I don't know I've just heard a lot of stories and stuff and I've heard a lot of stories of people in the chair and stuff for you know like, I think like 18 months or whatever, and getting stuff back. And funny enough there is one guy in the gym and he is just being trained by one of the trainers and he like took his first step after 3 years... I'll just keep going, trying you know (1st interview).

The anticipation of restored function from *exercise is restitution* stories acted on Daniel to motivate initial engagement in ABR. Furthermore, the desired outcome of walking again that was fostered by the *exercise is restitution* narrative acted as a facilitator to continued exercise at ABR. The hope for a specific or material outcome has been conceptualised in SCI by Smith & Sparkes (2005) as *concrete hope*. As the clients' comments suggest, hope in the *exercise is restitution* narrative was linked to the concrete outcome of a cure for SCI. However, this concrete hope for a cure was through ABR as opposed to medical or technological breakthroughs in traditional stories of restitution. As highlighted in chapter seven, taking action by searching for a cure represents a defiant attitude towards SCI. Furthermore, taking action is the *source* of people's hopefulness (Soundy et al., 2012). Therefore as Daniel's comments illustrate, people can maintain concrete hopes of recovery in the *exercise is restitution* narrative, even when there is no change in their circumstances. This finding echoes previous work which identified the narrative environment of ABR centres as one that supports clients' use of the restitution narrative (Perrier et al., 2013). Although the trainers did not explicitly promote ABR as a cure for SCI, ABR is characterised by intensive exercise programmes which aim to maximise an individual's physiological, functional and neurological potential (Jones et al, 2014). This is illustrated in the following extract from the Neurokinex website regarding the goal of ABR: "to stimulate the body to work as one unit again and if possible to re-establish some form of a link or pathway between the paralysed and functioning parts" (Neurokinex, 2014). In such a way, the *exercise is restitution* stories that clients' tell 'fits' with the restorative focus of ABR centres.

It was not only the environment of Neurokinex that facilitated stories of exercise is restitution; family and friends also helped sustain this narrative. As Frank (2013) explains, the restitution story is the most culturally preferred narrative; anyone who is ill or injured wants to be healthy again. As "contemporary culture treats health as the normal condition that people ought to have restored" (p.77), people are most comfortable hearing restitution stories. This preference for restoring health was reflected in the stories of *exercise is restitution* as they were co-constructed by family members and friends. For instance, as described in the previous chapter, these stories were constituted relationally in that family members would often be involved in the search for restitution opportunities and in the decision making process. Similarly, friends were also crucial in relationally sustaining this preferred narrative

structure. Friends played a role in reflecting on stories of the past that helped shape a possible future of restitution. This is exemplified in the following words from Thomas:

But at the moment if people say to me you've got to accept it to go forwards then like no, I won't you know. I won't ever accept it. I'll only accept it the day I die, maybe. I don't think I should accept it, there is always hope. If there is one percent, there is a 99% chance I will never ever walk or do anything again but there's always that one percent chance someone's got to have it why can't it be me? So, you never know and if you knew my life history and the things that have always happened and the things I've done. My mates say if there's any person that one day will get up and prove everyone wrong, it would be me. So, I've got to give it a chance, I want to walk in that boozier one day and go how about that, that was a poxy fucking 10 years but I'm back (1st interview).

As Thomas' story highlights, imposing the narrative structure of *exercise is restitution* is an interpretative process that looks back in time to project into the future (Sools et al., 2015). As Gergen (1994) explains, "we cannot separate 'who I am' from 'who I have been' and 'who I think, wish, hope, or fear I will be'" (p.190). For Thomas, the stories of his past-self; the life that he led before his injury, meant that he could not 'accept' a future without hope he will regain the life once lived before. As Soundy et al. (2013) warn, the restitution narrative draws upon an external source of hope (in this case ABR) that helps patients defy SCI, "but this reliance on an external source of hope may mean patients are unable to accept or acknowledge the present circumstances" (p.181). Furthermore, telling a story of *exercise is restitution* restricted Thomas' narrative imagination from narrating a future of any possibilities other than a cure. His "narrative map" only had one destination (Phoenix & Sparkes, 2006; Frank, 2013), which was 'walking again'. The dilemma with becoming fixated on restitution is, however, what happens when impairment remains and recovery is not forthcoming in the long term? The following remark from Thomas offers one possible outcome:

I'd love to walk out of here... I don't know, I'm a firm believer in never give up, you never know what's around the corner. Obviously I know it would be a miracle to get up and walk one day, just to even move my arms, get my hands working or something would be great. But never say never. I've seen people come and go who couldn't do certain things, and in years to come all of a sudden things started kicking in. So if I can keep the training up, and keep my body used to doing certain things then I'll always believe that something might happen. But if I didn't have that belief, I

don't think I want to be here really that would be the end of it. So, I have to have that belief (1st interview).

Driven by a desire to regain movement, and a belief that by keeping the training up recovery might happen, Thomas hints at the fragility of the *exercise is restitution* narrative. What happens if recovery is not forthcoming is clear for Thomas; he would be plunged into chaos. The *chaos narrative* is characterised by a plot with no order and a storyline that imagines life never getting better (Frank, 2013). Moreover, the chaos narrative is associated with hopelessness as all hopes of a future worth living are lost (Smith & Sparkes, 2005). As Frank (2013, p. 94) warns, “when restitution does not happen, other stories have to be prepared or the narrative wreckage will be real.” Thomas, it might be argued, was drawing upon the restitution narrative and its possibility of a restored self to avoid narrative wreckage and keep a less desired chaos narrative at bay. The *exercise is restitution* narrative is indeed useful in motivating people to engage in physical activity (Perrier et al., 2013). Critically however, Perrier et al. (2013) warn that a pre-occupation with restoration may restrict individuals from partaking in other LTPA opportunities which may be psychologically fulfilling and supportive of exercise maintenance over a longer period of time. In other words, the *exercise is restitution* narrative may act on people to keep them engaged in ABR with the hope of recovery, but preclude them from alternative, less outcome-directed activities such as sport (as highlighted in the previous chapter). Furthermore, the above comments highlight the complications, and possible dangers, with telling a restitution-based story. These include the possibility of narrative wreckage if recovery is not forthcoming and people do not have other narrative resources to draw upon.

As highlighted in chapter seven, the physiotherapists in SCI rehabilitation were aware of the possible dangers of telling a restitution based story. Their concern with restitution was rooted in the notion that the associated concrete hopes of recovery were false, unrealistic, unachievable, and prevented their patients from reconstructing their life story following SCI (Smith & Sparkes, 2005; Wiles, et al., 2008; Soundy et al., 2010). To manage these unrealistic hopes, at least as deemed by this group of people, the physiotherapists drew upon a particular narrative plot of acceptance as they tried to steer their patients towards the quest narrative and more realistic expectations of SCI rehabilitation. The quest narrative is defined by an individual seeking to gain something positive from their experience of injury (Frank, 2013). Furthermore the hopes associated with the quest narrative in SCI are transcendent hopes of a better future (Smith & Sparkes, 2005). In the context of Neurokinex, there were

some similarities and differences with how the trainers perceived they managed hopes and expectations of ABR. In contrast to the physiotherapists in the SCI centres, the trainers at Neurokinex reported that they were not pre-occupied with ensuring their clients accepted their SCI and did not have any pre-set goals in mind for their clients. The goals of ABR were set in partnership with the trainer and in this context the trainers were not restricted by the same time pressures as faced by the physiotherapists. There was therefore more freedom for clients to work towards their more preferred goals. However, if one of their clients was perceived to be working towards an unrealistic goal through ABR, the trainers, like the physiotherapists (chapter seven), did draw upon the goal setting process to try and manage their expectations:

Jemma (Trainer): A couple of people have asked me that on the phone, when they were enquiring. "What are your goals, what are you going to do?" And I'm like well I can't tell you that until you come in and you tell us what your goals are and I can see how functional you are. Then we can discuss the goals together so there are no pre-set goals that we have for each individual, I'm happy to work towards what anyone's goal is, as long as it's not too unachievable or unrealistic. If somebody had a completely unrealistic goal I wouldn't just out right tell them that was stupid, I will try and redirect their thinking a little bit. If somebody kind of has a goal that's quite kind of a big goal, I try and break it down into more manageable things to do with them. And explain how we're going to achieve those goals. If someone comes in and thinks that they are going to start moving their legs or whatever that's not something you can realistically achieve. It's trying to explain to them why it isn't happening, or why it might not happen at all; try and find other positives they can work towards. It can be quite hard sometimes to refocus them on to something else like how about we make your transfers better or we make your balance better.

Jemma's comments illustrate that, just like the physiotherapists, the trainers utilised the goal setting process to realign what they deemed as unrealistic goals to smaller, more achievable goals. In so doing, the trainers were also promoting a therapeutic plot where the client desired a realistic goal the trainer could help them achieve (Mattingly, 1994). This therapeutic plot was also embedded within clinical time as each client's neurological function and goals were formally monitored by an evaluation (the EVAL) process every six months (see previous chapter). With ABR aimed at being for lifelong participation, this iterative activity was far less frequent than in formal rehabilitation (every four weeks compared to every six months). Therefore the trainers at Neurokinex gave clients much more time to fully explore their capabilities in the hope that they would come to their own conclusions about

what would be realistically achievable. On the other hand, unlike the physiotherapists (chapter seven), the trainers at Neurokinex did not resort to additional strategies if unrealistic hopes and expectations remained. Instead, the trainers offered an alternative counter-narrative (Phoenix & Smith, 2011) to the dominant cultural narrative of restitution. This counter-narrative was that of exercise is medicine which promotes and supports stories of ABR that focused on the benefits on health and well-being.

Critical reflections: Box 9.1 – Rehab Junkie

For quite a long time Paul was sat in the waiting area with a wife of one of the clients. He later said to me that she was struggling with her expectations about her husband's improvements. Although he was improving in the gym, she couldn't translate these improvements into everyday situations. Therefore in her eyes she couldn't see the benefits of his exercise at Neurokinex. Paul told me that he thought many clients were stuck in the mentality of recovery, and were not in the mind-set of improving health and well-being which is the message they are trying to bring across at Neurokinex. This is the first time I have heard or seen of any family members talking about expectations. Whenever I have asked the trainers either on the gym floor, or in an interview, about expectations, they have said expectations are not something they have discussed with any family. I wonder if family and friends do have these concerns about expectations, but they just don't feel that they can discuss these with the trainers. Or maybe this example is an exception, and this was just something that came up in conversation with Paul.

When I pursued the topic a little further, Paul expressed how difficult it can be to manage hope and expectations. He drew upon the term rehab junkie to describe his initial engagement in ABR. He explained that he himself was a rehab junkie, and for him that meant that he was addicted to rehab and all he wanted to do was recover from his SCI. But a couple of years after his injury he hit the rehab wall. The rehab wall for Paul was when improvements plateau and you realise you cannot carry on at the same intensity at rehab. He said that he had hit the rehab wall and doesn't exercise as much anymore, he no longer sees himself as a rehab junkie. Despite acknowledging the existence of rehab junkies at Neurokinex, those clients telling stories of exercise is restitution, stories about how to manage these hopes and expectations were also silenced. The trainers were not offered any training or education for managing hopes and expectations, but they were advised not to make any unrealistic promises.

9.3 Exercise is medicine

Based on extensive research on the relationship between exercise and health, exercise as a form of medicine is an emerging concept of growing popularity within healthcare, academia and policy (Sallis, 2009; Neville, 2013). Regular exercise has been shown to improve physical and psychological health and well-being, as well as prevent secondary health conditions in people with SCI (see chapters two, three and eight). As Sallis (2009) describes, the evidence for the medicinal qualities of exercise is so robust it has been described as “the much needed vaccine to prevent chronic disease and premature death” (p.3). The *exercise is medicine* narrative provides an alternative story to restitution whereby participating in ABR is aimed at improving health and well-being whilst not focusing explicitly on a ‘cure’. As the previous chapter highlighted, all clients reported perceived improvements in their health and well-being from engaging with ABR. However in some stories, this was the fundamental motivation to continue being physically active. There are two dominant storylines within the *exercise is medicine* narrative told by people with SCI. The first storyline reads “I experienced an ailment, then I engaged in exercise, and the ailment is eased or eradicated”. In this instance, the “ailment” may be minor or severe, physical or mental, but it is separate from the original injury to the spinal cord. The following comment from Richard highlights how exercise can reduce the ailments associated with SCI:

Well I've had with my diet, a two stone weight loss and psychologically it's helped me a lot. It's something in my life, whereas I have a lot of lonely boring days. Yeah takes my mind of things, because when I have loads of time on my hands and not doing anything, I'm inactive. I think of the accident and my life in general and it's kind of depressing. So this has helped me psychologically because I was on anti-depressants and I've come off them now. I was on a load of medication, pain medication and what not, and I've come off that as well so that's since I've been doing this. I think this has helped to come off that, in the 12 months. It's been good for me because I didn't like the fact of all the medication I was on anyway, it was horrifying me. You know it was a great thing to get off that, so now it's very minimal now the medication I have to have... but when I did come here initially I had pain medication, bladder and bowel and some other important things. But a lot of those issues have been addressed now since I've been doing this, I feel a lot better. With the pain and medication side of it, that's good, and the bladder and bowel, that's a lot better (2nd interview).

Richard's story is an example of the secondary health conditions and decreased mental health associated with inactivity after SCI (Martin Ginis et al., 2012). He tells a story of increased weight gain and subsequent depression following his accident. Regular exercise

had enabled Richard to reduce his weight and manage other conditions including bladder and bowel issues. Furthermore, exercise through ABR was literally a form of medicine for Richard because it was perceived by him to be more effective in improving his mental health in comparison to prescribed medication. As a consequence of his improved physical and psychological state, Richard was able to stop taking medication for pain and depression completely. Stories of *exercise is medicine* such as Richard's reinforce the link between exercise and health for people with SCI and foster continued engagement in physical activity.

The second storyline within the *exercise is medicine* narrative speaks to stories of health maintenance and illness prevention. This storyline differs subtly from the first narrative concerning ailment relief and reads: "My health may be good now, but I exercise regularly for both health maintenance and illness prevention for the future". Rather than a focus on symptom alleviation and health improvement, these stories address maintaining existing health and guarding against future physical and mental decline:

Lee: I knew that it wasn't going to be any miracle worker or anything like that, it's literally the gym. The perfect gym for what I need as opposed to just trying to go to a normal gym and try using it whatever. So was just more for that, I knew I was just going to get healthier... like it (physical activity) didn't have any importance before my accident, you know it was nothing. I just took it for granted, like everything was working I wasn't old enough to have any serious issues so you know I was just ticking along. It wasn't that important at all... But obviously now, the effects of it are a lot more. So if I'm not physically active I'm just putting on weight and then it will make everything harder for me to do you know, transferring will be harder, my digestive system will get, not run properly because of you know, you know it's unhealthy. So it's important now, so here at the moment it's important... just general like losing weight, gain better shape and stuff. Obviously like you know, I can say unrealistic stuff like I wish I could walk out of here, but obviously that would just be a bonus. So there is no goal like that because I understand my injury is severe, it's a severe injury (1st interview).

Lee's *exercise is medicine* narrative differs slightly from Richard's story as it primarily addresses maintaining health and preventing physical decline. In essence, Lee's narrative might also be termed *exercise is "preventative" medicine*. Lee draws upon his narrative imagination to envisage a future of the detrimental effects of being inactive. He is driven to exercise regularly to reduce his weight, maintain his health and to remain independent as he gets older. In this instance, the culturally prevalent promise of exercise as a form of medicine (Sallis, 2009) persuaded Lee to start exercise, when it wasn't a priority

before his accident. In narrative terms, this is an example of the capacity of stories for “narrative ambush” (Frank, 2010). Drawing upon the work of Pierre Bourdieu’s concept of habitus, Frank (2010) proposed that people have a narrative habitus which he conceptualised as an inner library of stories. This narrative habitus predisposes people to hear certain stories as those that ought to be listened to, and others that are disregarded as “not for me” (Frank, 2010; Griffin, 2010; Smith, 2013). As Lee’s remark highlights, before his SCI his narrative habitus predisposed him to feel LTPA was not for him. It was only following SCI that a story of *exercise is medicine* ambushed his narrative habitus and found a place within his inner library.

Furthermore, as Lee’s story demonstrates, the *exercise is medicine* narrative provides an alternative to *exercise is restitution* whereby participating in ABR is aimed at improving health and well-being without the promise of walking again. In essence, it is a story of living well with SCI, and not a story of cure. Therefore the dangers associated with the *exercise is restitution* narrative are not present in this narrative. For Lee, ABR is comparable to a “normal gym” and he is not hoping for ABR to be a miracle cure from SCI. The expectations of the *exercise is medicine* narrative are aligned with ongoing ailment relief, long-term health and illness prevention. As such, those who buy into and live their lives by the *exercise is medicine* narrative develop a powerful *long-term* commitment to living an active lifestyle as there is no fixed endpoint goal. The hopes associated with the *exercise is medicine* narrative are closely aligned to those of the quest narrative; transcendent hopes for a better, healthier future (Smith & Sparkes, 2005; Soundy et al., 2013).

The *exercise is medicine* narrative could therefore be more beneficial, and more valued by physiotherapists in SCI rehabilitation, in promoting a physically active lifestyle through ABR. It has the promise to be the most ideal type of narrative and was the most promoted narrative by the trainers at Neurokinex. However, for some clients it was only after a prolonged period of time that they came around to telling a story of *exercise is medicine*. Reflecting the views of the physiotherapists in chapter seven, some clients at Neurokinex first told a story of *exercise is restitution* infused with concrete hope of recovery before their stories reflected a shift in narrative:

Oliver: I haven’t had expectations for ages now after the spinal cord injury. Before I did, in the first 5 years after injury you think oh yeah in 10 years I’m going to be alright. But I think I’ve gone past that stage now and any little improvement is a massive bonus sort of thing anyway. That’s how I see it... I always had in my mind

from day one I've always had that I want to get back on my feet and walk as like I was, but I know that won't happen sort of thing. But whatever I've got now is to maintain it and get as strong as possible. Live a bit of an easier life, it's cool, I've come to terms with it (2nd interview).

Oliver's story, like those of other clients, supports the notion that it can take many years for people to accept their SCI and no longer expect to regain the function they once had (Soundy et al., 2010; Van Lit & Kayes, 2014). As Oliver insinuates, once people have come to terms with the SCI, their stories of ABR represent a *shift* in narrative from *exercise is restitution* to *exercise is medicine*. Mirroring this shift in narrative, hopes also change with acceptance as they adjust from concrete hopes of recovery from ABR, to transcendent hopes of improved health and well-being through ABR. This shift in narrative and hope from recovery to exercising for health and well-being benefits is echoed in other physical therapies such as locomotor training (Jordan et al., 2013). Similar to the physiotherapists (chapter seven), this change in hope over time was recognised by the trainers as a common pathway of some of the clients at Neurokinex:

Louise (Trainer): I find generally people's goals tend to sometimes just die down and they adjust their main focus to just improve on everything that they can. Yeah I definitely noticed it from the beginning, you have the more goalsetting and then as they become a regular client it's more about a lifelong rehab for them. And it's generally improving general fitness and strength everywhere and as much as you can really.

Louise's comments highlight that some of the clients at Neurokinex came to their own conclusions, or moments of realisation (chapter seven), about what they could realistically achieve through ABR. The trainers were therefore aware of the temporal dimension of hope (Wiles et al., 2008; Soundy et al., 2010; Soundy et al., 2014b; Van Lit & Kayes, 2014) as it changed throughout participation in ABR. As mentioned earlier, although the trainers at Neurokinex recognised that their clients' hopes changed over time, they did not try and force a moment of realisation. Rather, they respected their clients' *right to hope* (Groopman, 2005), and perceived that whatever their clients' hopes of ABR were, they would be gaining benefits to their health and well-being by being physically active. Therefore, the trainers perceived their role was to develop a good rapport with their clients and provide interesting and challenging exercise routines to entice long-term commitment to ABR. Whilst the trainers further aimed to educate their clients about the likely outcomes to health and well-being of participating in ABR, they were not focused on trying to re-adjust their hopes of ABR.

Within the narrative environment of Neurokinex, the trainers valued and promoted stories of *exercise is medicine* over stories of *exercise is restitution*. However, although the *exercise is medicine* narrative does negate the dangers associated with restitution, it can depict an overly romantic story of LTPA and SCI. For Frank (2013), the quest narrative – which shares similar hopes to the *exercise is medicine* narrative – risks romanticising illness and disability. The risk of quest stories is that the transformation to embracing uncertainty and transcendent hope is depicted as too clean a process (Frank, 2013). In reality, living with SCI presents many recurrent moments of risk and uncertainty; the journey has many ups and downs, good days and bad days (Charmaz, 1991; Lohne & Severinsson, 2004a; Smith & Sparkes, 2004; Lohne & Severinsson, 2005). In essence, without concrete hopes of recovery, the *exercise is medicine* narrative depicts an idealistic approach to exercise. This is because transcendent hopes of a better future would suggest that people were seemingly on the road to accepting their SCI (Smith & Sparkes, 2005; Soundy et al., 2013). However, this was not the case for all clients who drew upon the *exercise is medicine* narrative:

Richard: But I've seen a psychiatrist and a psychologist and what not, and I've got a bit of an understanding, and they say I don't ever have to accept it as long as I make the most of my life what I can.

Interviewer: When you say you don't think you've accepted it, is accepting it to you being ok with it?

Richard: Yeah I think, it's just I don't think I ever will accept it. Being here I've seen more people who are more severely injured than me, and can do a lot less than me, and that makes me feel guilty the way I feel because, you know. They've even said to me I do brilliant, I motorbike still and it makes me feel quite bad like, when I feel down sometimes I think "oh I can do quite a lot of stuff" (2nd interview)

Richard's story represents a different paradoxical position on hope and acceptance. The paradoxical position of hope in possibility asserts that a person can accept their SCI, yet still have a defiant attitude towards the limits placed upon them by the SCI. (Soundy et al., 2013). This was not the case for Richard. On the one hand he exercises to improve his health and well-being, rather than as a cure for SCI. Furthermore, he was not seeking a cure through any other means (e.g. medical, technological etc.). However, he was adamant he will never accept his SCI. Therefore in this example the type of hope being drawn upon by Richard may have been that of *intransitive hope*. For Frank (2013) intransitive hope has no specified object or objective but leaves the future open. Through intransitive hope, people can tell a story of

exercise is medicine without having to accept their SCI, yet still hope for a life that “can be at least worthwhile and at best valuable” (Frank, 2013, p.205).

9.4 Exercise as undefined possibilities

As stated in the previous chapter, the narrative environment of Neurokinex was deeply rooted within their tagline of *redefining possibilities*. The intensive exercise programmes provided clients with a different story of LTPA and SCI that opened up new opportunities to be physically active. More importantly to the clients, they were able to try functional exercises (such as walking and crawling) that were off limits to them in formal rehabilitation. The notion of being able to participate in exercise, which in turn might lead to new possibilities (whatever those possibilities may be) following SCI, typified some of the stories of the clients at Neurokinex. In this instance, these clients were telling a story of *exercise is undefined possibilities*. For example, Stuart reflected upon his first experience of ABR as one that opened up exercise opportunities that he didn't think were possible anymore:

Yeah, even before I got injured I was very fit. I like being fit, there's no down side to being fit like. Its healthy, its keep you in good shape, there is no down side to it so, like for a while I thought after this you know, you can't be fit anymore, you can't do this exercise. You know I was very pleased the first time I came over and seen that you can... When they bought me in and showed me around, when they showed me you know you'll be doing this and this, I thought they don't know, they don't realise, they think I'm better than I am. But I was on everything they said I would be, I was doing things that I didn't think I would be doing for years. Didn't think I would ever be doing again. I was on a spin bike, just an ordinary spin bike that anybody else would be on. I was being supported and that you know, but I didn't think that was possible or could be done at all. But there I was! (1st interview)

In this extract Stuart reveals how shocked he was that he was going to be able to perform exercises and movements that he had considered off limits following his SCI. Before his injury, Stuart had embodied a physically active identity (see previous chapter). With high level tetraplegia, Stuart didn't think he would be able to maintain this identity and keep himself fit and healthy. With a focus on full body intensive exercise programmes, Neurokinex offered hope by redefining what was possible with a SCI. Yet, exactly what was hoped for was not disclosed. In stories of *exercise is undefined possibilities*, hopes and expectations of ABR were not defined, and in some instances, were never discussed. For many clients, their stories of *exercise is undefined possibilities* blurred the boundaries (Smith & Sparkes, 2008) with the other two narratives. On the one hand many clients drew upon the

exercise is medicine narrative as they talked about their desire to remain physically healthy following SCI. However, on the other hand, their motivation to partake specifically in ABR ran deeper than just physical health and well-being. These clients were simultaneously drawing upon aspects of the *exercise is restitution* narrative by using ABR to defy and challenge their SCI. Consider, for example, how George narrated his reasons for attending ABR:

I believe there are two options. I could either come up here and become physically active or I would just be in the house sitting around, especially with my injury becoming less and less fit and every day. I think it's really important to stay healthy and physical... the reasons why I came to Neurokinex is because I wanted to challenge the spinal cord injury that I have got and getting the most out of any potential help that there is out there... My reason is that I don't want to look back in 10 or 15 years' time and think what if I hadn't challenged it where could I have been. So that is my reasoning I just want to challenge it now while I am still fresh and young and then see where we can get to. But I can't, after doing this I can't see me stopping doing exercise on a regular basis anywhere in the near future I don't think. I think I will always keep at it now, and try and challenge everything until there is no more I can do (1st interview).

George's story of attending Neurokinex to challenge his SCI was framed by the *exercise is undefined possibilities* narrative which suggests he was open to whatever benefits ABR may bring. In other words, George's story was mostly concerned with challenging the injury in the present while the future was left open to emerge. Like others telling a similar story, specific goals of ABR, any hopes or expectations, were never disclosed. This is not to suggest that clients didn't have hopes of what ABR could provide them. Rather, these hopes remained unexpressed, or 'silent' (Lohne and Severissson, 2004a). The *exercise is undefined possibilities* may therefore be a specific example of an 'emergent' narrative. Accordingly, as Smith (2013) explains, "the person telling an emergent narrative does not want to specify too much of that narrative. They leave it open to emerge" (p.112). Leaving the future open to emerge is also characteristic of intransitive hope. As Frank explains, this hope "is believing in the future, and acting to bring that future into being, in the absence of any specific imagination of that future" (p.217). While the future is left open to new possibilities, George also contended that he could imagine being physically active for life. The *exercise is undefined possibilities* may therefore be understood as anticipating a story of *exercise is medicine*. However, if functional recovery was an outcome of participating in ABR, then the

exercise is undefined possibilities narrative also has the potential to emerge as a story of *exercise is restitution*.

Accordingly, the *exercise is undefined possibilities* narrative could be represented as a story in-between the other two narratives. Clients telling stories of *exercise is undefined possibilities* may therefore be understood as being in place of transition, waiting for the uncertain, and not knowing what the outcome of ABR will be. Uncertainty has been characterised as living in limbo, or in-between life chapters (Broom & Cavenagh, 2011; Jordan et al., 2013). For Becker (1997), uncertainty is a transitory state of being in the world and the act of being “suspended in social space” (p.119). Being in this social space where people are “neither one thing or another; or maybe both” (Turner, 1967, p.96) has been conceptualised in studies of narrative and illness as a *liminal space*. Liminality describes an experience of in-between and uncertainty where stories of illness and disability no longer fit into more established narrative types (Broom & Cavenagh, 2011; Bruce et al., 2014). Stories that draw upon the *exercise is undefined possibilities* may be further conceptualised as experiences of *pervasive liminality* (Bruce et al., 2014). Thus, although these stories are in the liminal space in-between the other two narratives, pervasive liminality points to the overlap with the other two narratives that are simultaneously drawn upon, or “borrowed” (Frank, 2013) in some clients’ stories. The position of the exercise is undefined possibilities narrative is illustrated in Figure 9.1.

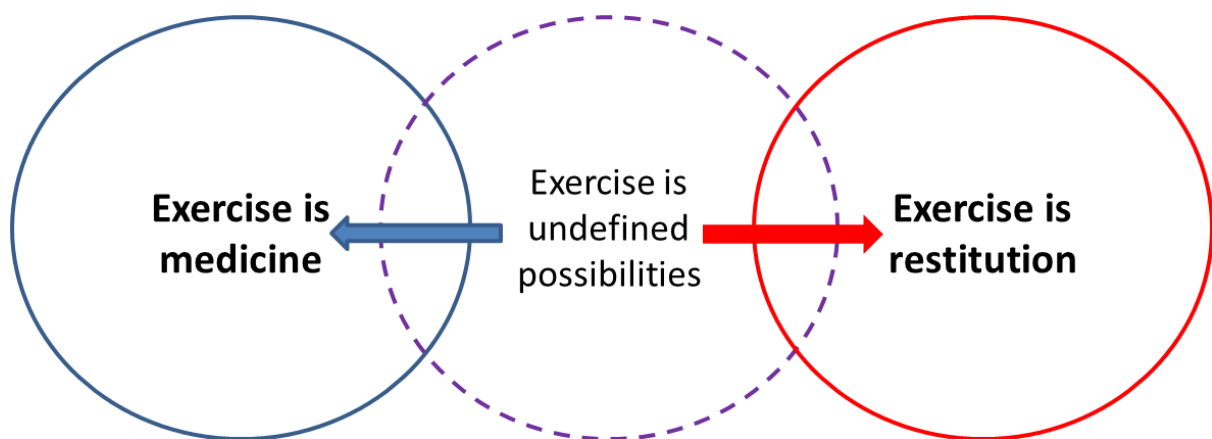


Figure 9.1: Narrative typologies

The clients whose stories hung on the *exercise is undefined possibilities* narrative were motivated to partake in ABR by the possibility of what this programme could offer them over other LTPA opportunities. However, this begs the question of how long would people buy in to this narrative and wait in the “holding room” (Jordan et al., 2013) of

possibility? While some clients remained committed to this narrative for the duration of the study (18 months), others could not sustain this narrative line:

Steve: And I didn't get as much out of it as I'd hoped. So I stopped after a few months.

Interviewer: So you said you didn't get as much out of it like you'd hoped for. What were you hoping to get out of it?

Steve: I wasn't hoping for a miracle, but I was trying to reconnect with some sort of muscles lower down, or any kind of benefit. I just wanted to be a bit more supple, perhaps have a few less spasms as well and yeah just generally feel healthier. I found it was no better than anything else I was doing before, and some of the things we did were just a bit weird really. Some of the wrestling, and things like that I found a bit strange it's a bit too intimate sometimes. And I didn't feel better for it necessarily (2nd interview).

It was only after Steve had terminated his engagement with ABR that he was willing to articulate what he hoped to achieve. As Steve's story suggests, his hopes of ABR were aligned with hope in possibility (Soundy et al., 2013). In this paradoxical position, people can accept their SCI, yet at the same time try and defy it by challenging the limitations placed upon them by their injury (see chapter seven). Steve admitted that on the one hand he didn't expect ABR to be the miracle cure to SCI, yet he was hoping for some connection to his paralysed body in addition to any health benefits. After a couple of months Steve perceived that ABR didn't offer him any benefits that he wasn't already achieving from other LTPA opportunities. This paradoxical position, unlike the *exercise is restitution* narrative, meant that Steve was able to partake in less outcome-directed activities such as sport alongside ABR.

As alluded to earlier, the *exercise is undefined possibilities* narrative is distinct from the other two narratives in that clients chose not to express their hopes and goals from engaging in ABR. This wasn't the case just in the interviews. These clients didn't reveal their hopes to their family, friends or their trainers at Neurokinex. One possible explanation for this is that clients were keeping their hopes to themselves to avoid disappointment if they didn't come to fruition (Lohne and Severissson, 2004b; 2006). Furthermore, clients may not have expressed their hopes to family and friends to avoid the distress it may cause them if those hopes were not fulfilled (Papathomas et al., 2015). Specifically, this may have been the case when family members were the first to discover Neurokinex and went out of their way to

facilitate participation in ABR (see previous chapter). The clients may therefore have been carrying out ‘emotional work’ as they were caring for and protecting these family members (Exley & Letherby, 2001; Papathomas et al., 2015). Another explanation as offered by George, was that clients didn’t perceive a need to share their expectations:

We don’t have specific chats about goals and expectations but he (trainer) knows where I want to be. And I don’t think we need to have the conversation because I believe he wants the best for me as well. He wants to get to a personal goal himself, a client who has reached their full potential. We don’t have specific conversations about it, but we both have a mutual understanding of where we want to get to and the expectations and realism of getting that (2nd interview).

George’s silence regarding his hopes and expectations regarding ABR was due to his understanding that his trainer already knew what he *really* hoped for. When stories of hopes and expectations were silenced, the trainers had to guess what these hopes and expectations may be. This guesswork, what might be called *narrative speculation* (Papathomas et al., 2015), led the trainers to invariably assume the clients were seeking recovery from their SCI.

Michael (Trainer): They don't really kind of let on what their expectations are to us and they don't really talk about it. I also don't think people would be 100% honest about their expectations either, I think they are quite reserved in what they tell you. I think deep down everybody wants to be better, everybody wants to be cured or fixed or something. But I don't think there are many people who would walk in and say that to your face, but I think deep down there's always that hope of "I'm actually going to get 100% better, I'm not going to be in a wheelchair any more" ... Clients tend to go "I just want to see where it goes", or umm in a half jokey way "yeah I want to walk." Umm, but whether they realistically expect that to happen I don't think that's the case. I think it's like yeah you would like to of course but, I don't think people necessarily expect that.

As Michael explained, the *exercise is undefined possibilities* is a common storyline drawn upon by clients. Whilst some clients hint at *exercise is restitution*, there are not many people that reveal associated concrete hopes of recovery. The trainers at Neurokinex believed this may be the case for one of two reasons. Firstly, as ABR is a relatively new ‘therapy’, they perceived that not many people knew what to expect at Neurokinex. Secondly, the trainers believed that some people seeking recovery were not comfortable disclosing goals that revolved around recovery. Either way, silenced hopes and expectations were difficult for the trainers to manage. This silence created a tension for the trainers between a concern over not pushing clients to disclose their hopes and expectations, and a desire to know what the

clients were seeking from ABR. The danger with silencing stories is that it blocks the storyteller from new ways of storying their experience (Sparkes & Smith, 2002). Furthermore, as Frank (2013) warns, silencing stories is a problem when people eventually do need to talk. In his exploration of life-as-normal illness narratives, Frank contends: “For many people, a communicative practice that inhibits developing ways of talking about illness means that when the illness gets worse, they will not have the capacity to say what has to be said. Talking about illness takes practice” (pp.196-197). Therefore, the danger with clients silencing stories regarding hopes and expectations emerges when they are actually seeking hopes of recovery. In this instance the clients may not have the narrative resources to draw upon and share their stories if they get to the point where they want to talk about hopes and expectations. Moreover, the trainers may not have the opportunity to offer alternative stories such as *exercise is medicine* for the clients to shape their exercise experience by if recovery is not forthcoming.

Critical reflections: Box 9.2 – What is missing is the story?

In a dialogical narrative analysis, interpretation of stories is achieved by working on a set of questions. One of the questions Frank (2010) proposes to ask of the data when interpreting stories is “which details might have been expected but are omitted?” (p.107). It was while contemplating this question I thought about what the participants at Neurokinex were communicating about their hopes and expectations of ABR. I had already identified two narrative types: *exercise is restitution* and *exercise is medicine*. There were stories of *exercise is restitution* that focused on walking again while stories of *exercise is medicine* focused on health and fitness. This was initially very clear cut to me. The differences between these narratives were obvious. But then I noticed there were some stories that I heard in Neurokinex where hopes and expectations were omitted. For some participants, their narrative plot included no clear goals. I started to pay more attention to their interactions with their friends, family and trainers. Again, I noticed that hopes and expectations were not discussed. This troubled me. What narrative type were these stories drawing from? Were these stories simply *exercise is medicine* and *exercise is restitution* simultaneously in action? On the surface these stories focused on health and well-being, but some participants wanted more. But they didn’t specify what this more was. Then I realised that not talking about hopes and expectations differentiated these stories from the other two narratives. I decided the *exercise is undefined possibilities* should be considered as a type of narrative as it provides healthcare professionals (HCPs) with an identifiable thread in the fabric of a person’s story that has potential consequences for the storyteller (Frank, 2010).

9.5 Summary

In this chapter, I identified three narrative types that clients at Neurokinex drew upon to structure their experiences of ABR. In particular I emphasised the work these stories did for the clients in terms of their motivation to engage with ABR and their associated hopes. The *exercise is restitution* narrative specifically prescribed exercise through ABR as the means by which a person could return to their former able-bodied self. Although restitution does not have to explicitly focus on walking (Perrier et al., 2013), clients who framed their stories by this narrative were exercising in the hope of regaining the ability to walk. The danger with this narrative was that clients were aligning their stories of concrete hopes of recovery which left them without other narrative resources if recovery was not forthcoming. The *exercise is medicine* narrative presents as an ethical ideal type of story (Frank, 2013) as clients are engaging with ABR to improve their health and well-being without the promise of walking again. The associated hopes with this narrative were seemingly transcendent hopes of a better future. However this was not the case universally as people could draw upon this narrative without “accepting” their SCI. Finally the *exercise is undefined* possibilities existed in the liminal space between the other two narratives, borrowing from *exercise is medicine* and hinting at *exercise is restitution* but prescribing to neither. The hopes of ABR in this narrative are silenced as clients have intransitive hopes of a future that is left open to emerge. The danger with silencing stories of hopes and expectations comes when people do want to have these discussions in the future and are left without the narrative resources to negotiate these conversations. The uses of these narrative types to help HCPs better understand people’s experience of SCI and LTPA is addressed in the general discussion in the next chapter.

Chapter 10: Conclusions and Implications

10.0 Overview

In this thesis I have offered a deep understanding of what can constrain and facilitate a physically active lifestyle for people with spinal cord injury (SCI) (chapters three and eight). As part of this, the research also uniquely demonstrated the role of pleasure in facilitating continued engagement in leisure time physical activity (LTPA). Furthermore I have highlighted the dilemmas of promoting physical activity (PA) for physiotherapists in SCI centres. These included a lack of training and education in health promotion and a concern over the false hope of recovery from LTPA opportunities such as activity-based rehabilitation (ABR) (chapters six and seven). This concern over false hope raised by physiotherapists was realised as some of the clients drew upon an *exercise is restitution* narrative in that they were participating in ABR in the hope of walking again. However, the *exercise is restitution* narrative was not explicitly promoted by the trainers at Neurokinex. Rather, they valued an *exercise is medicine* narrative with a focus upon ABR for improving and maintaining lifelong health and well-being (chapter nine). In this concluding chapter I address the *so what?* question (so what is the point of this research?) by detailing the empirical, methodological and practical implications of this research.

10.1 Empirical implications

This thesis sought to address key research aims and questions (see chapter two) in order to understand the role of LTPA in relation to people with SCI. In doing so it was the first empirical study to develop knowledge pertaining to the barriers, benefits and facilitators of LTPA for people with SCI throughout rehabilitation and from discharge from this context into the community. An understanding of the factors that impacted LTPA participation was achieved through a meta-synthesis of qualitative research (chapter three), an exploration of PA in SCI rehabilitation (chapter six) and in a community-based LTPA initiative ABR (chapters eight and nine). The purpose of the meta-synthesis was to gather existing knowledge on the barriers, benefits and facilitators of PA among people with SCI. This is the first synthesis of qualitative research on LTPA and SCI and contributes original and significant knowledge by revealing some of the psycho-social complexities that impact on LTPA participation. Furthermore, this was the first empirical study to investigate physiotherapists' beliefs about PA for people with SCI and their experience of PA promotion within the UK and Ireland. This study made a contribution to the literature by identifying in chapter six that, whilst physiotherapists do value the importance of PA for people with SCI, active PA promotion remains largely absent within the UK and Ireland SCI rehabilitation

context. In addition to the meta-synthesis, the study also advanced empirical knowledge by exploring the factors that impact LTPA in ABR. Embracing a narrative approach allowed for rich, detailed description and nuanced interpretation of participants' experiences of SCI and LTPA. For example, in chapter eight this study illuminated the importance of the forgotten dimension of pleasure as a benefit and a facilitator of continued engagement in ABR.

Furthermore this study sought to explore hope in people with SCI and how hope and expectations are managed by physiotherapists in SCI rehabilitation and by community-based health practitioners. The findings reported in chapter seven showed how the physiotherapists used therapeutic employment to manage hopes and expectations of SCI rehabilitation. It adds to the literature by identifying the therapeutic actions the physiotherapists drew upon to try and co-construct a narrative plot of acceptance in interactions with their patients. Thus, chapter seven answers calls to understand the ways in which physiotherapists support, enhance and manage hopes in SCI (Wiles et al., 2008; Van Lit and Kayes, 2014). The findings reported in chapter nine illustrated how the trainers drew upon certain actions to manage hope and expectation of ABR (e.g. goal setting). Yet the trainers at Neurokinex were not preoccupied with trying to force a "moment of realisation" or encourage their patients to "accept" their injury.

In terms of empirical findings, as highlighted in chapter nine, the research also identified various narrative types that were circulating within the narrative environment of Neurokinex. Each narrative type was aligned with a certain type of hope which posed different challenges for the trainers at Neurokinex to manage. Chapter nine also connects to narrative theory by highlighting the importance of stories for "acting on" people and shaping their experiences of hope. For example, the *exercise is restitution* narrative was drawn upon by clients as they were motivated to engage in ABR through concrete hope of a cure from SCI. PA accounts that resonate with recovery and the restitution narrative can be problematic. This research echoes the warning of others (e.g. Smith & Sparkes, 2005; Frank, 2013), in that the restitution narrative can have dangerous consequences on health and well-being when the hope of recovery is not fulfilled. Specifically, concrete hopes can limit people's ability to envision a range of potential outcomes other than a cure, and inhibit other areas of life such as community integration (Frank, 2013; Nunnerley et al., 2013).

Empirical advancements were also made in chapter nine through the identification of two new narrative types; *exercise is medicine* and *exercise is undisclosed possibilities*. The

exercise is medicine narrative, fostering transcendent hopes of a better, healthier future, depicted an idealistic approach to exercise. The *exercise is undisclosed possibilities* was distinct from the other two narratives in that hopes and expectations of ABR were not disclosed. Moreover, this narrative was conceptualised as a story in-between the other two narratives, borrowing from each as required. Building a typology of narratives recognises that experience of ABR and hope follow from the availability of narrative resources circulating within Neurokinex. Thus, identifying three typologies allowed me to identify the different underlying plots of stories of ABR, the consequence of telling these stories, and how hopes and expectations were managed in this context.

The empirical findings also highlight how disability is understood by the participants. For many of the clients, despite problems with the medical model – as noted in the literature review in chapter two – this model framed how they understood disability. This is reflected in the exercise is restitution narrative which promotes a belief that disability should be overcome (chapter nine). Despite the utility of the social model and social relational model of disability, few people understood their disability through these models. That said, the meta-synthesis (chapter three), and the clients at Neurokinex (chapter eight), highlighted that many of the barriers that restricted LTPA were both physically (e.g. decreased well-being and biological impairments) and socially created (e.g. environmental influences such as a lack of finances). In this sense, the social relational model provides a more nuanced understanding of how disabled people can be restricted in what they do. Moreover the physiotherapists (chapter six) recognised the importance of PA for people with SCI beyond the medical model of disability which typically prioritises physical and functional restoration outcomes. Yet on the other hand, the physiotherapists enacted psycho-emotional disablism – as outlined in the social relational model – by denying their patients the option to remain physically active through ABR. The practical implications and critical reflections of these empirical findings are discussed below.

10.2 Methodological implications

This thesis contains several methodological implications for synthesising qualitative research. The five stages of the meta-synthesis (Walsh & Downe, 2005; Hammell, 2007; Thomas & Harden, 2008) appeared at the outset to be straightforward and in essence easy to follow. There were however some limitations that arose due to the methodology of the meta-synthesis, which may have importance in future work. Firstly, studies that included other

disabilities outside of SCI were excluded because the results did not always identify the participants' quotes with their disability. Secondly, some original data points were not included in the data extraction process because the authors did not explicitly relate participant quotes to LTPA. Therefore there could be other benefits, barriers and facilitators to LTPA that remain to be addressed, but which could not be definitely identified. Whilst the meta-synthesis in chapter three does not claim to have identified all of the barriers, benefits and facilitators to exercise, it has recognised the relationship between these factors and PA promotion. Therefore researchers in the future need to be clearer when presenting their research findings to avoid these issues.

Thirdly, in regards to the conduct of a meta-synthesis, I would recommend that authors of future meta-syntheses keep a detailed reflexive journal of their decision making process throughout the five stages. A highly developed reflexive ability is required when conducting a meta-synthesis (Walsh & Downe, 2005) to enable the researchers to apply the same standards of quality to their work as they expect of the papers they are synthesising. Comparing and synthesising different data sets between different qualitative methodologies was not easy. However I aimed to preserve the meaning from the original text in the form of raw data as far as possible. As Walsh and Downe (2005) explain, this is because the “goal is to increase understanding, leading to a greater explanatory effect, rather than to aggregate and merge findings” (p.209). I first compared and synthesised the data for barriers, benefits and facilitators of PA individually before generating analytical themes across the data sets. I therefore presented the final themes as a collective of barriers, benefits and facilitators of PA.

The fourth implication relates to judging the quality of the research papers. As stipulated in chapter three, this stage has been proposed as vital in a meta-synthesis to avoid including studies with methodological deficiencies and drawing unreliable or misleading conclusions (Hammell, 2007; Thomas & Harden, 2008; O'Connell & Downe, 2009; Gough et al., 2012). This is however not a straightforward task. There is no agreed method by which to make this assessment for quality and rigour which is reflective of the larger issue around judging qualitative research in general (see chapter four). Many meta-syntheses use a pre-determined universal list to appraise quality which is potentially problematic if this does not take into account the different philosophical positions and epistemological assumptions underlying different qualitative research methods (Sparkes & Smith, 2009). For example, pre-determined lists of criteria have been used to judge the quality of research studies within both sports (Jefferies et al., 2012) and health literature (Hammell, 2007; O'Connell & Downe,

2009). Having a pre-determined set of quality criteria can limit meta-syntheses in two further ways:

Firstly, studies including important and robust findings may often utilize unorthodox yet perfectly valid methods. Such studies would be excluded from many systematic reviews. Secondly, some studies, whilst perhaps being methodologically flawed in part, or with overall findings that do not appear important or relevant, may still be able to offer important insights into phenomena, or may contain important findings in part, whilst not doing so as a whole (Weed, 2006, p.130).

Alternative criteria should be used to judge qualitative research whereby judgements are made based upon lists of criteria that are appropriate to the form of inquiry (Sparkes & Smith, 2014). These criteria are not universal or static in nature, but are lists of characterising traits that can change over time and in different contexts. To compensate for differences in methodology, I drew upon the considerations for judging qualitative research in meta-syntheses as proposed by Garside (2014). Garside recommends that papers in qualitative systematic reviews should be appraised based on criteria of trustworthiness (epistemological aspects), theoretical considerations and practical (technical) considerations. Garside suggests that rather than using one checklist, this method allows for “careful consideration of the study within its own terms” (2014, p.11).

All that said, difficulties did arise when judging the quality of the research papers because some did not explicitly identify their conceptual/theoretical framework and form of inquiry. As Garside (2014) notes, qualitative papers frequently focus on the research findings at the expense of detailing their methodology. Overall there is a lack of consensus in the qualitative community over the methodological detail required for a research article (Garside, 2014; Sparkes & Smith, 2014). By ignoring the methodological detail of the research, researchers are not providing the specificity or reflexivity that is required to reflect on such issues as the strengths and weaknesses of their chosen qualitative methodology (see Sparkes & Smith, 2014). It would be of benefit for future qualitative research to therefore include details of their methodology and the conduct of their work. This is because “without a picture of what was done, it is difficult to make any judgement about whether this is likely to produce meaningful, trustworthy findings” (Garside, 2014, p.10).

Lastly, this thesis contains methodological implications that extend our knowledge and understanding of narrative inquiry. In particular, this thesis advances the methodological

application of narrative by drawing upon a range of data sources in a dialogical narrative analysis (see chapter nine). A dialogical narrative analysis is an innovative approach that treats stories as actors in people's lives. Therefore the primary concern is with *how stories act* (Frank, 2010, 2012). Through observational and reflective data I was able to record and deliberate on the *actions* of the clients at Neurokinex as they acted out elements of their stories in interactions with their trainers, family, friends and peers. Applying Frank's (2010, 2012) dialogical questions to all three data sources (i.e. interview, observational and reflective data) lead to novel findings regarding people's motivation to participate in ABR. For example, through a dialogical narrative approach I was able to conceptualise a narrative typology regarding the clients' stories of hopes and expectations of ABR. The first two narrative types – *exercise is restitution* and *exercise is medicine* – were conceptualised through both what was *said* in interviews and what was *done* in narrative's everyday practice (Gubruim & Holstein, 2009). Stories of *exercise is restitution* aligned with hopes of walking again while stories of *exercise is medicine* conveyed a hope for living well with SCI. However, I was also observing stories in action whereby hopes and expectations were not defined and in some instances remained unexpressed, or silent. It was only after further dialogical analysis and reflection of this observational data, I was able to identify a third narrative type; *exercise is undefined possibilities*. In this instance the field notes were critical in identifying a narrative thread that was silenced from both interviews and everyday interactions (see dialogical narrative analysis in chapter four and critical reflections: Box 9.2 in chapter nine).

10.3 Practical implications

There are several practical implications that arise from this research for people with SCI, healthcare professionals (HCPs) such as physiotherapists, the healthcare system and other health practitioners in community-based PA opportunities. These practical implications are aimed at improving PA promotion and reducing the barriers to PA for people with SCI.

10.3.1 Knowledge translation

With regard to findings from chapter six, to implement PA promotion as a structured and integral component of physiotherapy practice, the dynamic process of knowledge translation needs to be more effective across the macro, meso and micro fields. To achieve this, effective knowledge translation requires the combined efforts of national policy makers, healthcare

systems, HCPs, academics and community-based expertise and people with SCI (Morris & Williams, 2009; WHO, 2013; Tomasone et al., 2014; Wong et al., 2015).

Starting with knowledge production, at the macro level PA policy makers need to engage with academics to drive meaningful guidelines on PA. Despite guidelines developed in other countries (see Martin Ginis et al., 2011), there are currently no evidence-based comprehensive PA guidelines in the UK or Ireland for people with SCI. These guidelines need to be developed and embedded into UK and Ireland policies for PA if they are to be received and utilised by physiotherapists. As part of this, guidelines should include specific details about the types, amounts and intensity of physical activities to achieve health benefits. Developing comprehensive, realistic and sustainable PA guidelines specifically for people with SCI could address the barrier raised by physiotherapists in chapter six regarding a lack of knowledge and confidence in PA prescription and promotion (Martin Ginis et al., 2011). In addition, these guidelines may be able to assist other health practitioners in community-based PA opportunities (e.g. including personal trainers in commercial gyms) prescribe exercise for people with SCI. Furthermore the policy makers, HCPs and health practitioners tasked with promoting regular engagement in PA for people with SCI, should “look beyond the “usual suspects” (e.g., reducing risk of type II diabetes, coronary heart disease, obesity etc.) and bring the notion of pleasure into the foreground of policymaking” (Phoenix & Orr, 2014, p.101).

To also address the translational gap (Ferlie et al., 2012) between knowledge produced at the macro level to translated knowledge used in healthcare practice at the micro level, appropriate training needs to be delivered. This resonates with the work of Wong et al. (2015) and McGrane et al., (2015), which acknowledge that without appropriate guidelines and training, HCPs have insufficient knowledge to provide lifestyle education for patients with SCI. Therefore physiotherapists need training on PA and SCI to equip them with sufficient knowledge to prescribe and promote PA. This part of the knowledge translation process should occur at both the meso and micro levels, and be facilitated by engagement with those who have expertise of evidence based research (e.g. academics) (see Tomasone et al., 2014). At the meso level all university degree courses should educate physiotherapists on the importance of PA both as a component of their treatment in rehabilitation, and promotion of lifelong health and well-being in the community. As Walkeden and Walker (2015) advocate, physiotherapy training must equip students with the knowledge and skills required if they are to actively engage in health promotion.

Furthermore, whilst cognisant of shrinking budgets and time limitations, it is essential that hospitals deliver mandatory training to enhance HCPs understanding of their role in health promotion (Walkeden & Walker, 2015). This training should continue at the micro level with rehabilitation centres delivering workshops on PA to establish PA promotion as a structured and integral component of physiotherapy practice. Consistent with research in stroke rehabilitation (Morris et al., 2014), the physiotherapists in chapter six perceived that patients' lack of motivation to be physically active was fixed and that they were unable to influence behaviour change. This is an important finding considering that behaviour change and fostering adherence to treatment plans in physiotherapy practice is possible (Jack et al., 2010; Heaney, 2012; McGrane et al., 2015). Yet this finding is not surprising considering physiotherapy degree courses in UK universities lack training on psychological interventions and theories relating to health promotion and behaviour change (Heaney, 2012).

Therefore, to maximise the potential of PA promotion resulting in an increase in PA uptake, physiotherapists could additionally be trained in psychosocial factors such as motivational interventions to foster positive health behaviour change (Morris et al., 2014; McGrane et al., 2015). Narrative has also been identified as one avenue to translate knowledge about PA to physiotherapists "in a way that attracts people, holds their attention, and gets under their skin" (Smith et al., 2015, p.310). Smith et al. (2015) demonstrated that evidence-based stories were effective in disseminating PA research knowledge to HCPs in SCI rehabilitation. Moreover, these evidence-based stories can be utilised by physiotherapists as a resource to share knowledge on PA with people with SCI and move them towards behaviour change. These evidence-based stories could also be used as a resource for people with SCI to share with their peers about how to become physically active.

The evidence suggests that knowledge about health promotion through PA could be improved not just in physiotherapists, but also in other HCPs. For example, a survey study of HCPs (mainly doctors) in SCI rehabilitation across four countries (UK, the Netherlands, Belgium and Republic of Ireland) reported inadequate training in health promotion and behaviour strategies which limited their ability to deliver health advice to people with SCI (Wong et al., 2015). Such a lack of training is noteworthy given the national policy in the UK that stipulates all HCPs have a responsibility to deliver health promotion (NHS Future Forum, 2012). Under the "Making Every Contact Count" policy, every contact made with a patient by any HCP is viewed as an opportunity to deliver brief interventions on health behaviours including PA (Walkeden & Walker, 2015).

10.3.2 Physical activity is more than sport

The knowledge on PA shared with physiotherapists and other HCPs through various levels also needs to include the diversity of PA opportunities available to people with SCI. A key reason for this is that the focus of PA in the SCI centres as highlighted in chapter six, was predominantly sport. This could be problematic for at least two reasons. Firstly, sport can be empowering and promote health and well-being, but if physiotherapists simply promote this kind of activity, there is the risk of perpetuating the ‘supercrip’ narrative. A supercrip is a disabled athlete that with courage, dedication and hard work proves that the odds can be beaten, the impossible can be accomplished and one can heroically triumph over the ‘tragedy’ of disability (Smith & Sparkes, 2012). The concern with supercrip athletes, as noted by Berger (2008, p.648), “is that these stories of success will foster unrealistic expectations about what people with disabilities can achieve, what they should be able to achieve, if only they tried hard enough”. This, in turn, could lead to blaming disabled people who do not wish to, or are unable for bodily, structural or economic reasons, to engage in disability sport (Smith & Sparkes, 2012). Equally, whilst for some people a supercrip narrative might interpellate (i.e. hail) them into disability sport, for others it can push people away from sport (Smith, 2013). Secondly, an exclusive focus on sport could discourage activity for those who do not like sport. Indeed, people with SCI often report wanting to do other activities over sport, including aerobic exercise, resistance training and wheeling (Martin Ginis et al., 2010a). Thus, a wider range of options to be physically active need to be offered.

One such PA option available in the community is ABR as offered at Neurokinex. However, the physiotherapists in chapter six did not promote this option due to the various concerns they held. In addition, as reported in chapter eight, the clients at Neurokinex perceived that their HCPs were unwilling to consider ABR as a viable PA opportunity for people with SCI. The concerns with ABR, such as promoting an unrealistic restitution narrative and concrete hope of walking again, might be more broadly located within physiotherapists’ professional ethic to keep their patients safe (Morris et al., 2014). Drolet and Hudon (2015) propose that physiotherapists should analyse and justify their ethical decision making by considering multiple ethical standpoints. In this instance this would include: the positive and negative consequences of attending ABR; respecting the rights of their patients to maintain a physically active lifestyle; appreciating their patients’ beliefs and opinions about ABR and upholding the professional values of physiotherapists to promote lifelong health and well-being in people with SCI whilst keeping patients safe. To facilitate

this, closer communication and engagement should be implemented at the micro level between physiotherapists in SCI centres and the health practitioners working in community initiatives such as ABR. Physiotherapists need to be informed of the time, effort and resources required to take part in ABR, as well as the likely impact on health and well-being. This would enable patients to make informed decisions with their physiotherapists about engaging in such programmes (Jones et al., 2014; Petersen et al., 2013).

10.3.3 Support within the healthcare system

In addition to knowledge translation practices, there needs to be support within the healthcare system to facilitate a physically active lifestyle for people with SCI. Consistent with research in other countries such as Sweden and New Zealand (Mulligan et al., 2011), the physiotherapists in chapter six located barriers to PA promotion within the healthcare system. Predominantly there was a perception that many people with SCI are unable to access PA opportunities because they do not have the support to do so (lack of social support, restricted finances and geographical isolation etc.). The findings reported in chapter eight highlighted the importance of family and friends in overcoming the barriers to participating in ABR. Furthermore, the clients at Neurokinex were also aware of the multitude of barriers that would prevent their peers with SCI from engaging in PA opportunities such as ABR. To overcome these barriers, provisions need to be made to support people with SCI to be physically active in line with policies by the United Nations (UN) and World Health Organisation (WHO).

The human rights model of disability, grounded in the UN convention on the rights of persons with disabilities, states that everybody has the right to attain the highest standard of health “without discrimination on the basis of disability” (United Nations, 2006, p.20). This includes State Parties providing rehabilitation services and programmes for people with disability to “attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (see Appendix A). For this to apply to people with SCI, these rehabilitation programmes and services need to include PA opportunities. The WHO (2013) has suggested a number of ways to address rehabilitation services for people with SCI that the UK and Ireland healthcare systems should embrace. Furthermore, the physiotherapists themselves can address the constraints of their healthcare system by educating and advocating that PA is an important part of SCI rehabilitation (Mulligan et al., 2011). Indeed, in line with the social relational model of disability, all HCPs should act as disability allies in addressing common disability issues for

their patients (Roush & Sharby, 2011). Therefore community-based LTPA initiatives also have a responsibility to seek support from the healthcare system to make these LTPA options more accessible for people with SCI.

10.3.4 Critical reflections on narrative and physical activity promotion

Although it is undisputed that PA provides multiple benefits for people with SCI, the results of this thesis support the need for a more critical approach to PA and SCI. As highlighted in chapters seven and nine, the *exercise is restitution* narrative may pose dangerous consequences for an individual when the “false” hope of recovery is not forthcoming. However, this is not the only risk with promoting PA to people with SCI. One concern is that by promoting the *exercise as medicine* narrative, this in turn promotes a neoliberal health role (Smith & Perrier, 2014). Smith and Perrier (2014) comment that the health role in this context “calls on the individual to be a responsible citizen who must personally take care of his or her own health by doing things like exercising regularly” (pp.98). This attitude negates any social responsibility and leaves the individual accountable for being physically active. In other words, the *exercise is medicine* narrative aligns with the individualist mentality of the medical model of disability. This can however be problematic for disabled individuals because it neglects the social factors that restrict activity.

As the meta-synthesis in chapter three demonstrated, people with SCI were taking an active role to responsibly take care of their body and health. However, despite developing a sense of body-compassion and wanting to be physically active, there were still multiple environmental barriers that prevented people from participating in PA. Moreover, the findings reported in chapter eight revealed how clients at Neurokinex had to rely on external sources of funding to participate in ABR. Due to the high cost of individual sessions, a lack of financial resources was a barrier to increased engagement in ABR and prevented many clients recommending ABR to others with SCI. The neoliberal health role therefore risks ignoring societal aspects of being able to participate in PA (i.e. such as the high cost of specialist community based PA opportunities for disabled people) and consequently overlooks disablism and social oppression (as understood in the social relation model of disability) (Smith & Perrier, 2014). When an individual is motivated to exercise, but cannot because they are unable to access any PA opportunities, this could negatively impact upon their health and well-being. Furthermore, the *exercise is medicine* narrative, with a focus on the medicinal benefits of exercise, may not motivate those with SCI who want to exercise

simply for pleasure (chapter eight) because the pleasurable aspects of being active are largely ignored when the focus is on walking again.

Another concern with promoting PA is that a preoccupation with sport and exercise may inhibit psychological growth and well-being in other ways. For example, Kleiber and Hutchinson (1999) caution that “vigorous physical activity (and particularly sport) is at best a temporary palliative to ‘the crisis’ of physical disability for spinal injured men and at worst an impediment to a more complete personal transformation following the injury experience” (pp.135-136). The authors suggest that the desire for men to be physically active is brought about by cultural ideals which value a hyper-masculine hero narrative following illness and injury. Participating in sport may therefore perpetuate the ideology that men are valuable solely for their strong and able bodies rather than providing any alternative narratives. This may prevent men with SCI from expressing masculinity in ways outside of physical power and strength and value other dimensions of the self. Furthermore, HCPs and health practitioners need to be aware that initial PA experiences following SCI can actually heighten distress. As Day (2013) warned, PA can highlight the limitations associated with SCI and it is only by overcoming these struggles and difficulties that post-traumatic growth can be achieved.

A further dilemma with PA promotion is the need for people to be sensitive to the narratives they promote regarding PA. Appreciating stories as ‘actors’ in people’s lives (Frank, 2010, 2012), HCPs and health practitioners need to recognise the subtle differences between narrative types. Moreover, they need to understand not only the reasons why a person chooses to tell a particular story, but the type of hope these narratives offer and the possible limitations and dangers associated with telling that story. The typologies of narrative presented in chapter nine, allow the storyteller – be it the person with SCI or HCP – to critically reflect on the narrative that guides them and the influence it has on their broader lives (Frank, 2103). From a listener perspective, a narrative typology can aid HCPs and health practitioners in listening to people with illness and injury as the narrative types help the listener to untangle the different, and sometime contradictory, narrative threads of a story (Frank, 2013; France et al., 2014). It is therefore a valuable tool for those HCPs and health practitioners promoting PA and implementing PA interventions, to categorise these narrative typologies and act upon them when necessary.

In addition, HCPs and health practitioners need to promote a range of PA narratives as the more narratives available, the greater the chance that people can find one that fits their experiences of PA (Smith & Sparkes, 2009). As Smith (2013) advocates, HCPs and health practitioners “can ambush people in contexts like rehabilitation by increasing the narrative resources people have access to, thereby expanding the number of narratives that are allowed to act – to do things for and in people” (p.117). Drawing upon the pleasure of ABR highlighted in chapter eight, this variety of narratives should include the “potential pleasures of physical activity that incorporate the different places, temporalities and relationships in which it can be experienced” (Phoenix & Orr, 2014, p.101).

10.4 Concluding thoughts and future research possibilities

In this chapter I have summarised the empirical, methodological and practical implications of my research. The limits of this research reside in the questions that remain unanswered. Thus, I now conclude by discussing future research avenues to answer these questions. One potential area of future research is to explore the suggested knowledge translation practices that were highlighted in the practical implications. Research would be needed to investigate if more training and education could enhance HCPs ability and intention to prescribe PA to people with SCI. There is a growing body of literature within the domain of health and exercise psychology that addresses knowledge translation of PA research to people with SCI and HCPs (e.g. Tomasone et al., 2014; Gainforth et al., 2015; Smith et al., 2015). However, these practices are not currently being undertaken within the UK and Ireland.

Furthermore, the concerns raised by the physiotherapists regarding the potential promotion of false hope of recovery in PA opportunities, such as ABR in chapters six and seven, need to be addressed. For example, this research supports previous work (e.g. Smith & Sparkes, 2005; Frank, 2013) that highlights the potential negative consequences on health and well-being from storying exercise as restitution and engaging in ABR in the hope of recovery (see chapters three and nine). Nevertheless, there is scant longitudinal research that has addressed the long term impact of exercising for restitution. While this research did have a longitudinal component (18 months), it was not a long enough duration of time to answer specific questions. Future research may address whether narratives of exercise at PA opportunities such as Neurokinex differ a year post injury compared to 5 years post injury? Similarly, do the narratives told change according to age, gender and type of SCI? A

longitudinal approach should also be accompanied by an investigation into how the health practitioners in community based PA opportunities manage hope and expectation over time.

To understand how HCPs in SCI rehabilitation and health practitioners in the community manage hope and expectation, the use of conversation analysis is appealing for future research. Conversation analysis differs from narrative analysis in that it focuses on the study of talk-in-interaction (Wilkinson & Kitzinger, 2008). One of the underpinning assumptions of conversation analysis is that talk is understood as a form of *action*: “the focus is on what people *do* with talk, rather than just on what they say” (Wilkinson & Kitzinger, 2008, p.54). Conversation analysis has long been suggested as a method to research into interactions between patients and HCPs (e.g. Drew et al., 2001; Barnes, 2005; Parry et al., 2014). Drawing upon these examples, conversation analysis could be used to study the everyday conversational actions such as the careful use of language, as highlighted by the physiotherapists in chapter seven. This would enable a more nuanced understanding of what the physiotherapists do with their talk to influence how a patient experiences hope following SCI. In so doing, training can be given for people to become more reflexive about how they talk, what the implications might be for fostering hope during conversations, and how talk might be changed when interacting with people in order to create stories that do not hold so tightly to the hope of wanting to walk again. This would help to guide HCPs balance the difficult task of assisting patients to be realistic about the outcomes of rehabilitation whilst not undermining their need for hope (Harvey et al., 2012). Moreover, this research would also be applicable to the health practitioners in community-based initiatives such as Neurokinex. In this context it would be of interest to explore the type of hope the trainers promote in interactions whereby they encourage their client to *think about moving* parts of their paralysed body as they exercise.

Lastly, one other important omission from this research is the stories of the friends and family who were a vital source of social support to the clients at Neurokinex. The clients emphasised the significant role their family and friends played in facilitating their continued engagement in ABR at Neurokinex (chapter eight). Moreover, during the extended period of time at Neurokinex I learned that family and friends also experience distress when their loved ones became injured. Indeed, as previous research has shown, caring for a friend or family member following serious illness and injury can be a difficult and emotionally challenging task (e.g. Boschen et al., 2005; Dickson et al., 2010). It is therefore important that the stories of family members and friends are explored to understand their experiences of SCI and

further appreciate the social construction of narratives. Future research may examine questions relating to how the hopes of family and friends influence those of the person with SCI. For example, what types of narratives frame the stories of family and friends following SCI? How do these stories act on the person with SCI?

Overall, this research has answered many questions regarding the impact of LTPA for people with SCI. In addition, this thesis includes many practical implications and inspired future research questions to assist effective promotion of health behaviour through PA. My hope is that this research makes a contribution to the lives of spinal cord injured people by addressing some of the barriers that violates their human right to lead a physically active lifestyle.

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Appendices

APPENDIX A

Convention on the Rights of Persons with Disabilities (United Nations, 2006)

Article 25 – Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f. Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

Article 26 - Habilitation and rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;

- b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Article 30 - Participation in cultural life, recreation, leisure and sport

1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
 - a. Enjoy access to cultural materials in accessible formats;
 - b. Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
 - c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
2. States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
3. States Parties shall take all appropriate steps, in accordance with international law, to ensure that laws protecting intellectual property rights do not constitute an unreasonable or discriminatory barrier to access by persons with disabilities to cultural materials.
4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.
5. With a view to enabling persons with disabilities to participate on an equal basis with others in recreational, leisure and sporting activities, States Parties shall take appropriate measures:
 - a. To encourage and promote the participation, to the fullest extent possible, of persons with disabilities in mainstream sporting activities at all levels;
 - b. To ensure that persons with disabilities have an opportunity to organize, develop and participate in disability-specific sporting and recreational activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;

- c. To ensure that persons with disabilities have access to sporting, recreational and tourism venues;
- d. To ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities, including those activities in the school system;
- e. To ensure that persons with disabilities have access to services from those involved in the organization of recreational, tourism, leisure and sporting activities.

The impact of physical activity in spinal cord injury rehabilitation

Dear Sir/Madam

As a member of MASCIP, we are hoping that you will consider helping us with a research project we are conducting on spinal cord injury, rehabilitation, physical activity, health, and wellbeing. Due to the aims of the research we are interested in speaking with physiotherapists who are currently working within spinal injuries units or have recently (within one year) left this environment.

The research is led by Dr Brett Smith (Loughborough University) and conducted by PhD researcher Toni Williams. We are very interested in exploring experiences of physical activity in SCI rehabilitation. This would involve 1 interview arranged at a time and place convenient to you. In the interview we would like you to tell us, in your own way and at your own pace, about your experiences of spinal cord injury rehabilitation as a physiotherapist. There are no 'right' or 'wrong' answers. It is your experiences, and what you want to tell us about them that we wish to hear. We expect the interview to last between 1 and 2 hours. We hope that the findings will assist in developing awareness and knowledge regarding how best to promote health and well-being for spinal injured adults through physical activity.

With your permission, the interview will be digitally recorded and then transcribed for analysis. No one beyond the research team will have access to the contents of the interview. No member of MASCIP is part of the team, and as such will not have access to your personal information. The oral interview data will remain confidential. For example, real names will not be used and place names will be changed. The use of personal data conforms to the University data protection guidelines and will be anonymised throughout the process. Should you wish, we would be very happy to share the results of our study with you and discuss our findings.

Should you willing to be interviewed, or wish to discuss the project further, then please contact either Toni Williams [T.L.Williams@lboro.ac.uk] or Dr Brett Smith [B.M.Smith@lboro.ac.uk].

Yours sincerely,

Toni Williams and Dr Brett Smith

Peter Harrison Centre for Disability Sport

School of Sport, Exercise and Health Sciences

Loughborough University

APPENDIX C



School of Sport, Exercise and Health Sciences
Loughborough University
Loughborough
Leicestershire
LE11 3TU

Introductory Participant Information

Project Title: Health and wellbeing of people with SCI in activity-based rehabilitation

Introduction: My name is Toni and I am a doctoral researcher at Loughborough University with The Peter Harrison Centre for Disability Sport. The aim of my research is to explore people's quality of life and wellbeing as they move through the active rehabilitation programme at Neurokinex.

Purpose: We know a lot about the benefits and barriers to being physically active in general, however we know very little about the benefits of an active based rehabilitation programme. We want to understand what benefits there are to doing active rehabilitation in Neurokinex and what you think about the programme. We want to hear about your experiences, as these matter the most, so that we and Neurokinex can learn from your experiences and produce better programmes to help the spinal cord injured community.

What's involved: We want to interview you, in other words have a conversation, about your experiences of physical activity and Neurokinex. Ideally we would like to speak with you on three separate occasions over the period of a year for about an hour at a time. This will help to understand the process of active rehabilitation. I would like to invite you take part in this research project however it is up to you to decide whether or not to take part and you are free to withdraw at any time without giving a reason. All personal data will be kept confidential conforming to data protection guidelines and interviews will be recorded, transcribed and anonymised. No third party, including Neurokinex, will have direct access to your data.

Next step: If you are willing to participate please provide your contact details and email this form back to Neurokinex, or contact me directly on the below email or phone number. We can discuss the project in more detail and arrange the first interview for before you start active rehabilitation.

Many thanks

Toni

Toni Williams

Name:

Phone:

Email:

Researcher: Toni Williams, t.l.williams@lboro.ac.uk, 07800500978

Researcher: Dr Brett Smith, b.m.smith@lboro.ac.uk, 01509 222737

The impact of physical activity in spinal cord injury rehabilitation**Adult Participant Information Sheet**

	Lead Researcher	Researcher
Name:	Brett Smith	Toni Williams
Address:	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU
Email:	B.M.Smith@lboro.ac.uk	T.L.Williams@lboro.ac.uk
Contact:	01509 222737	07800500978

What is the purpose of the study?

The broad purpose of this study is to examine physiotherapists' views of physical activity for people with spinal cord injury (SCI). The aims are to explore 1) the role of physiotherapy in in-patient SCI rehabilitation, 2) the role of physiotherapy in out-patient SCI rehabilitation, 3) the use of physical activity in SCI rehabilitation.

Who is doing this research and why?

Brett Smith from Loughborough University will be leading the research. Toni Williams (PhD researcher) will be conducting the interviews and analysing the data. This study is part of a PhD research project supported by Loughborough University.

What will I be asked to do?

You will be involved in an interview. Each interview will last approximately 1 – 2 hours. In the interview you will be asked a series of questions that focus on:

- (a) your experiences of rehabilitation for people with SCI
- (b) your experiences of physical activity within rehabilitation for SCI
- (c) your role as a physiotherapist within SCI rehabilitation

Once I take part, can I change my mind?

Yes! After you have read this information and asked any questions you may have, we will ask you to complete an Informed Consent Form. However if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason, and you will not be asked to explain your reasons for withdrawing.

Are there any risks in participating?

Due to the nature of interviewing and the purpose of the study, there is the possibility that you may experience some mild distress, (for example in recalling unpleasant or upsetting experiences). If you do please note that at any time you do not have to answer any question and you can command the tape recording to be stopped. You may also terminate the interview when you wish. If you do experience distress, a number of professional support networks that, if you so wish, and without any questioning from the researcher, are available.

Will my taking part in this study be kept confidential?

The use of personal data in Loughborough University conforms to data protection guidelines and all efforts will be taken to maintain your confidentiality throughout the research. For example, the interviews will be tape-recorded and transcribed. Your real name will not though be used in these transcripts or thereafter in any public document or talk. Places (e.g. where you live), names of family members, members of health organisations, doctors, health professionals, etc. you may talk about will also be changed. All data will be transcribed into a password protected computer. Recordings and transcripts will be kept in a locked cabinet in Loughborough University. Only the people involved in the project will have access to the information. All information, including tapes and transcripts, will be destroyed within ten years of the completion of the investigation. You can also contact the lead researcher at any time after the interview has taken place and inform him that you want your data withdrawn from the study. It will be done so immediately and without any questions being asked as to why.

I have some more questions; who should I contact?

Dr Brett Smith

What will happen to the results of the study?

The results of the study will be published in public documents. These include professional journal articles and health magazines. The results will also be used in presentations. It is hoped the results will help understand the role of physical activity within SCI rehabilitation.

What if I am not happy with how the research was conducted?

If you are not happy with how the research was conducted, please contact Mrs Zoe Stockdale, the Secretary for the University's Ethics Approvals (Human Participants) Sub-Committee:

Mrs Z Stockdale, Research Office, Rutland Building, Loughborough University, , Loughborough, LE11 3TU. Tel: 01509 222423. Email: Z.C.Stockdale@lboro.ac.uk

The University also has a policy relating to Research Misconduct and Whistle Blowing which is available online at [http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm).

**Exploring the impact on health and wellbeing in people with spinal cord injury
as they move through an active rehabilitation programme at Neurokinex**

Client Participant Information Sheet

	Lead Researcher	Researcher
Name:	Brett Smith	Toni Williams
Address:	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU
Email:	B.M.Smith@lboro.ac.uk	T.L.Williams@lboro.ac.uk
Contact:	01509 222737	07800500978

What is the purpose of the study?

The broad purpose of this study is to examine people's health and wellbeing as they move through this activity-based rehabilitation programme. The aims are to explore 1) the impact of exercise participation on health and wellbeing, 2) why people engage in exercise for rehabilitation, 3) how barriers to exercise were overcome.

Who is doing this research?

This research is led by Dr Brett Smith (Loughborough University). Toni Williams (PhD researcher) is a collaborating researcher who conducts the interviews, participant observation and focus groups.

Once I take part, can I change my mind?

Yes! After you have read this information and asked any questions you may have, we will ask you to complete an Informed Consent Form. However if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason, and you will not be asked to explain your reasons for withdrawing.

How long will it take?

Any interviews and focus group work will last approximately 1 hour.

What personal information will be required from me?

During the interview, you will be asked a series of questions that focus on:

- (a) your experiences of SCI
- (b) your reasons for engaging in exercise rehabilitation, and
- (c) the impact of exercise upon your psychosocial health and well-being

Are there any risks in participating?

Due to the nature of interviewing and the purpose of the study, there is the possibility that you may experience some mild distress, (for example in recalling unpleasant experiences). If you do please note that at any time you do not have to answer any question and you can command the tape recording to be stopped. You may also terminate the interview when you wish. If you do experience distress, a number of professional support networks that, if you so wish, and without any questioning from the researcher, are available.

Our previous experience of interviewing however has found that it is pleasurable experience. We have also found that participants with physiological and psychological health issues found it useful because they were providing knowledge that would help others struggling with similar experiences.

Will my taking part in this study be kept confidential?

The use of personal data in Loughborough University conforms to data protection guidelines and all efforts will be taken to maintain your confidentiality throughout the research. For example, the interviews will be tape-recorded and transcribed. Your real name will not though be used in these transcripts or thereafter in any public document or talk. Places (e.g. where you live), names of family members, members of health organisations, doctors, health professionals, etc. you may talk about will also be changed. All data will be transcribed into a password protected computer. Recordings and transcripts will be kept in a locked cabinet in Loughborough University. Only the people involved in the project will have access to the information. All information, including tapes and transcripts, will be destroyed within ten years of the completion of the investigation.

What will happen to the results of the study?

The results of the study will be published in public documents. These include professional journal articles and health magazines. The results will also be used in presentations. It is hoped the results will help to improve the psychosocial health and well-being of people with SCI and their families.

I have some more questions who should I contact?

Dr Brett Smith

What if I am not happy with how the research was conducted?

The University has a policy relating to Research Misconduct and Whistle Blowing which is available online at

[http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm).

**Exploring the impact on health and wellbeing in people with spinal cord injury
as they move through an active rehabilitation programme at Neurokinex**

Trainer Participant Information Sheet

	Lead Researcher	Researcher
Name:	Brett Smith	Toni Williams
Address:	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU	School of Sport, Exercise & Health Sciences, Loughborough University, Loughborough, LE11 3TU
Email:	B.M.Smith@lboro.ac.uk	T.L.Williams@lboro.ac.uk
Contact:	01509 222737	07800500978

What is the purpose of the study?

The broad purpose of this study is to examine people's psychosocial health and wellbeing as they move through this active rehabilitation programme. The aims are to explore 1) the impact of exercise participation on health and wellbeing, 2) why people engage in exercise for rehabilitation, 3) how barriers to exercise were overcome.

Who is doing this research?

This research is led by Dr Brett Smith (Loughborough University). Toni Williams (PhD researcher) is a collaborating researcher who conducts the interviews, participant observation and focus groups.

Once I take part, can I change my mind?

Yes! After you have read this information and asked any questions you may have, we will ask you to complete an Informed Consent Form. However if at any time, before, during or after the sessions you wish to withdraw from the study please just contact the main investigator. You can withdraw at any time, for any reason, and you will not be asked to explain your reasons for withdrawing.

How long will it take?

Any interviews and focus group work will last approximately 1 hour.

What personal information will be required from me?

During the interview, you will be asked a series of questions that focus on:

- (a) your experiences of working with people with SCI
- (b) your experiences of activity-based rehabilitation, and
- (c) the impact of exercise upon your clients' psychosocial health and well-being

Are there any risks in participating?

Due to the nature of interviewing and the purpose of the study, there is the possibility that you may experience some mild distress, (for example in recalling unpleasant experiences). If you do please note that at any time you do not have to answer any question and you can command the tape recording to be stopped. You may also terminate the interview when you wish. If you do experience distress, a number of professional support networks that, if you so wish, and without any questioning from the researcher, are available.

Our previous experience of interviewing however has found that it is pleasurable experience. We have also found that participants with physiological and psychological health issues found it useful because they were providing knowledge that would help others struggling with similar experiences.

Will my taking part in this study be kept confidential?

The use of personal data in Loughborough University conforms to data protection guidelines and all efforts will be taken to maintain your confidentiality throughout the research. For example, the interviews will be tape-recorded and transcribed. Your real name will not though be used in these transcripts or thereafter in any public document or talk. Places (e.g. where you live), names of family members, members of health organisations, doctors, health professionals, etc. you may talk about will also be changed. All data will be transcribed into a password protected computer. Recordings and transcripts will be kept in a locked cabinet in Loughborough University. Only the people involved in the project will have access to the information. All information, including tapes and transcripts, will be destroyed within ten years of the completion of the investigation.

What will happen to the results of the study?

The results of the study will be published in public documents. These include professional journal articles and health magazines. The results will also be used in presentations. It is hoped the results will help to improve the psychosocial health and well-being of people with SCI and their families.

I have some more questions who should I contact?

Dr Brett Smith

What if I am not happy with how the research was conducted?

The University has a policy relating to Research Misconduct and Whistle Blowing which is available online at
[http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing\(2\).htm](http://www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm).

Health and wellbeing of people with SCI in activity based rehabilitation

**INFORMED CONSENT FORM
(to be completed after Participant Information Sheet has been read)**

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethical Approvals (Human Participants) Sub-Committee.

I have read and understood the information sheet and this consent form.

I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in the study.

I understand that I have the right to withdraw from this study at any stage for any reason, and that I will not be required to explain my reasons for withdrawing.

I understand that all the information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers unless (under the statutory obligations of the agencies which the researchers are working with), it is judged that confidentiality will have to be breached for the safety of the participant or others.

I agree to participate in this study.

Your name _____

Your signature _____

Signature of investigator _____

Date _____

Researcher: Toni Williams, t.l.williams@lboro.ac.uk, 07800500978
Researcher: Dr Brett Smith, b.m.smith@lboro.ac.uk, 01509 222737

APPENDIX H

Interview Guide Physiotherapists

Introduction

- 1) Full professional title, age, years' experience, time in current job?
- 2) Please tell me about how you became involved in neurological physiotherapy?
(probe for experience, why specialise in SCI rehab)

SCI Rehabilitation

- 3) What do you see as the role of physiotherapy in in-patient SCI rehabilitation?
- 4) Can you please describe the stages in SCI rehabilitation? (probe from initial hospital entry to discharge)
- 5) How do you manage hope and expectation within rehabilitation?
- 6) Do these hopes and expectations change over time throughout rehabilitation?
- 7) How do you think your relationship with a patient impacts upon their rehabilitation?

Physical activity in hospital

- 8) What do you define as physical activity?
- 9) What are your thoughts on doing PA in SCI rehabilitation?
- 10) What is the role (if any) of PA in SCI rehabilitation?
- 11) What opportunities for PA are there in the hospital?
- 12) Are these PA opportunities compulsory/well attended?
- 13) Do you promote these PA opportunities? How? Where?

Physical activity in the community

- 14) What is the role of physiotherapy in out-patient SCI rehabilitation?
- 15) What opportunities are there for people to be physically active post-discharge?
- 16) Are you able to promote PA opportunities for people with SCI in the community?
- 17) Are PA opportunities in the community promoted in the hospital? (in the form of leaflets, advertisements, guest talks)
- 18) Do you think it is important for people with SCI to be physically activity in the community? Yes or no - why?
- 19) Are you aware of activity-based rehabilitation opportunities for people with SCI? (such as Project Walk [USA], Walk On [Australia], Neurokinex [UK])
 - a. If yes – what is your understanding of this programme?
 - b. If no – it will be explained.
- 20) Would you consider recommending this type of PA? Yes or no – why?

APPENDIX I

1st Interview Guide Clients

Grand Tour Questions

1. Tell me something about yourself/your life?

Pre-SCI profile – Experiences with exercise before injury

1. Tell me about your lifestyle before you were injured?
2. What did you most like to do?
3. How would you describe your level of physical activity?
4. What kinds of exercise/sport did you participate in?
5. How regularly did you participate in exercise/sports?
6. How did you spend your weekends and free time?
7. How important was physical activity in your life?

Injury

1. Can you tell me how long ago you were injured?
2. How did it happen?

Hospital Rehabilitation

1. What do you remember about the hospital rehabilitation process?
2. Was there an event that was particularly helpful to you during rehab?
 - a. How did you change as a result of the event?
3. What is your impression of recreational therapy?
 - a. (Probe for exercise/ sport as a form of therapy?)
4. Tell me about your participation in physical activity?
5. How do you feel about the programmes?
6. What if any physical activities were promoted by staff (and which staff)
 - a. why were they promoted or not?
7. Was anything discussed about being active in the community? What?

Leaving the spinal unit

1. How prepared were you for leaving the spinal unit?
2. If you had to go through the process again what would you do differently?
3. What tips/advice would you give to someone in the same position?
4. What were the best/hardest things about leaving the spinal unit?
5. How did the spinal unit prepare you for returning to live in the wider community?
6. Who are the most important people influencing your ability to be back in the community?

Post-SCI profile

1. How have things changed for you after the injury? (Probe for dramatic changes)
 - a. How do you feel about these changes?
 - b. What have you done to deal with these changes?
 - c. How did you learn these strategies?
2. Has your relationship with friends and family changed?
3. Are there any things that have not changed?
4. What are the emotional challenges that you have had to overcome since your injury?
5. What do you most like to do now?

Pre-Neurokinex

1. Why are you going to Neurokinex?
 - a. What are your reasons/motivations?
2. How did you find out about it?
3. How important is it for you to be physically active or participate in fitness activity?
4. What are the perceived benefits from exercising?
5. How often do you attend Neurokinex?
6. What are you hoping to achieve?
 - a. Do you have an end goal?
7. How do you go about setting goals and sticking to them?
8. Do you exercise outside of Neurokinex?
 - a. Yes/No – why?
9. Have your attitudes towards physical activity changed after the SCI?
 - a. How?

APPENDIX J

2nd Interview Guide Clients

1. It's been a year since our last interview, how have you been?

Neurokinex

2. In your own words could you please tell me a story that represents your overall experience of Neurokinex? (probe for a beginning, middle and end)
3. What does activity-based rehabilitation mean to you?
4. What would a typical session look like? (probe about exercises)
5. What is the outcome from participating in ABR?

Motivations/expectations/goals

6. What first motivated you to participate in ABR?
7. Have these reasons changed since you started the programme?
8. Did you have any hopes or expectations before you started of ABR?
9. Do you have any future hopes or expectations?
10. We spoke last time about your goals from ABR, have you achieved any of these goals?
11. Do you have any future goals you would like to achieve? How?
12. Have you discussed your ongoing hopes and expectations with your family?
 - a. Yes – what is their opinion?
 - b. No – why not?
13. Have you discussed your ongoing hopes and expectations with your trainer?
 - a. Yes – what is their opinion?
 - b. No – why not?

Other therapies

14. Do you participate in any other physical activities or sports?
15. What do you see as the role of PA in SCI rehabilitation?
16. What advice would you give to other people about PA and SCI?

Future plans

17. Fast forward a year, will you maintain a PA lifestyle?
 - a. Yes – what would your lifestyle look like? (probe key people, barriers, staying motivated)
 - b. No – why not?

APPENDIX K

Interview Guide Trainers

1. Can you describe Neurokinex to me?
2. How did you get involved at Standing Start/Neurokinex?
3. What is your role as a trainer?
4. What are the challenges of this role?
5. What does activity-based rehabilitation mean to you?

Health and Wellbeing

6. Do you see an impact on a client's health and well-being whilst exercising?
7. What do you feel are the benefits from activity-based rehab?
 - a. How is this improved?
8. Apart from your role in exercise, what else do you offer to clients?
 - a. (Advice bladder/bowel, pressure sores, relationships etc.?)
9. What things can people take outside of the centre into their everyday lives?

Expectations

10. What are peoples' first expectations of activity-based rehab?
 - a. Clients, partners/family, yours of your clients, any others?
11. How do you manage these expectations?
12. Do people manage to realistically achieve their goals/targets?
13. What about expectations 6 months down the line?
 - a. Clients, partners, yours of your clients, any others?
14. Can you describe to your relationship with your clients?
 - a. Examples of good and bad relationships with clients?
15. If a client was going to tell you a story a year down the line from starting activity-based rehab what do you think they would say?

Standing Start/Neurokinex

16. What images do you think the names Standing Start and Neurokinex conjure up?
17. Have there been any changes from Standing Start in Cambridge to Neurokinex in Watford?
 - a. Impact on clients/staff/participation?
18. Is there an impact from people going to other centres or forms of PA?
19. What do you think people's opinions of Neurokinex are outside of the centre?

APPENDIX L

Professional support and information networks

If you need to talk anyone after the interview, the following are some possible people or organisations that you might consider. None are linked with the project and all offer confidential support.

1) Spinal Injuries Association. What do they provide?

- Confidential Advice
- Information
- Support

How can I contact them?

Freephone Advice Line: 0800 980 0501 (Weekdays from 9:30am to 1pm and 2pm to 4:30pm) • Text SIA and your enquiry to 81025 (charged at your provider's standard rate). Email: adviceline@spinal.co.uk

2) Helen Smith

consultant clinical psychologist and specialist in spinal cord injury

Tel. 020 8909 5521 Email: helen@shrink.eclipse.co.uk

3) Back-Up. What do they provide?

- Confidential Advice
- Information
- Peer Support

How can I contact them?

Telephone: 020 8875 1805. Email: OutreachandSupport@backuptrust.org.uk