WOMEN, SPORT AND SPINAL CORD INJURY: NARRATIVE AND RESILIENCE

by

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A Thesis Submitted towards the degree of

Master of Philosophy
in Sport and Health Sciences

at

Exeter University

2010

UNIVERSITY OF EXETER
SCHOOL OF SPORT AND HEALTH SCIENCES

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Submitted by **Sacha Evelyn Pedro** to the University of Exeter as a dissertation towards the degree of Master of Philosophy in Sport and Health Sciences, March, 2010

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ABSTRACT

This dissertation examines the lived experiences of four previously active women who suffered traumatic spinal cord injuries and became disabled. In particular, it works to illuminate the differences in women's experience of disability compared to previous research on men and disability. Gendered experiences of embodiment and impairment are revealed and a new narrative type – the resilience narrative - is outlined. Some practical implications of these illuminating experiences are offered.

Word Count: 43,254

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CHAPTER 1: INTRODUCTION

This study is based on the lived experiences of four women who were highly physically active and subsequently became disabled through sport or physical activity. I became involved in this research because, as a woman, I was interested in finding out if there were any differences between how active men and women responded to traumatic spinal cord injury. In a prior Master's degree thesis, I completed a case study on an active young man who had a traumatic spinal cord injury; undeniably, that work has inspired me to delve further into disability studies. I soon found myself interested in women and disability, and I realized that there was little work done on women who were highly active prior to their injuries. Having seen how high levels of physical activity can have an effect on a man's response to such injuries, I was motivated to discover if the response was similar in active women.

This research attempts to address a number of theoretical and empirical gaps in the current research available. In Chapter 2, I outline the current research and theories in a number of areas: disability, the body, narrative, identity and gender. While each of these topics touches on an area related to my research topic, this chapter also helps to demonstrate the lack of research conducted on previously active women who received traumatic spinal cord injuries and are now disabled.

In Chapter 3, I discuss the methodology followed during the course of the research and writing process. A purposive sampling process was used, and participants were contacted with the help of the Back-Up Trust. Informed consent was obtained from all participants, and confidentiality has been maintained primarily through the used of pseudonyms.

Chapter 4 reviews the results of this qualitative research in relation to the current research and theories outlined in Chapter 2. It covers four main topics of interest that arose during the interview process: the body; narrative; identity; dependence and independence; and relationships and motherhood.

Finally, Chapter 5 discusses the implications of this research and outlines how it helps to fill in the theoretical and empirical gaps in the current field. In

addition, it covers some limitations of the study, and possible future research directions.

In the beginning, I was nervous about conducting interviews with these women. After all, I am a woman without any known impairment, talking and attempting to understand the life experience of women identified with disabilities. I worried about how they would perceive my questions, and about whether my interpretations of their stories would be negatively affected by my lack of impairment. However, I was quickly drawn into their stories, and at once feeling awed at the variety of their experiences and impressed by their resilience in the face of adversity. I hope that this research does their stories justice.

CHAPTER TWO: LITERATURE REVIEW

2.1 Disability

2.1.1 What is it?

Although it may seem simple, 'disability' is in reality a difficult concept to define. One reason for this is because, as Grönvik (2007) points out, the notion of 'disability' has encompassed distinct meanings across decades, cultures, and ideologies. Likewise, Kearney and Pryor (2004) suggest that, even within academia, one's definition of 'disability' varies according to discipline, paradigms and personal views. The actual definition and conceptualisation of the term 'disability' has been the centre of much argument and debate, for the different paradigms of disability not only reflect, but also determine: our values and beliefs about disability; how we define disability; the causes of disability; and disability-related social policy, resources and services (Kearney & Pryor, 2004).

Nevertheless, it is important that we offer a working definition of 'disability', for without a one, improving the lives of those who are disabled becomes difficult. As Gordon and Rosenblum (2001) said, in the modern world, "the person with a visible impairment inhabits a body rejected by society – and the consequences of that are much the same as they are for those in race and sex minority groups" (pp. 13-14). They go on to explain that it is important to define what disability can be, since without knowing this we will not know how to proceed with policy. Further:

> People with impairments – just like those in stigmatized race, sex and sexual orientation categories – are presumed to lack or be unable to realise the values and attributes the culture esteems. They are not expected to be dominant, active, independent, competitive, adventurous, sexual, self-controlled, healthy, intelligent, attractive, or competent. Like those in other stigmatized categories, they risk being *seen as nothing but a problem* (Gordon & Rosenblum, 2001, p. 14)

Given the variety of definitions of disability, how might we better understand the concept? Given that the different definitions have come into existence based on certain models of disability, one way to understand the term is to examine these models. Today, there seem to be two main approaches to understanding disability. One family of definitions focuses on individual or medical characteristics, sometimes known as 'social deviance'; however, the other considers disability as a

socially constructed phenomenon, produced by barriers of different types, and is often known as 'social oppression' (Grönvik, 2007). In other words, the two primary ways of defining disability were conceived by examining disability via opposing paradigms (or looking through different 'lenses'): the social deviance lens and the social oppression lens (Thomas, 2007). In following sections, I will be reviewing the basis, benefits, and drawbacks of each of these approaches to disability.

2.1.2 The Medical Model of Disability
2.1.2.1 What is the Medical Model?

The medical model of disability is based on the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (ICIDH), in which impairment denotes: "any loss or abnormality of psychological, physiological, or anatomical structure or function"; disability "is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being"; and handicap "is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual" (Wood, 1980, pp. 27-29). However, the World Health Organisation eventually reviewed this definition of disability and remodelled it in the International Classification of Functioning, Disability and Health (ICF). The ICF's classification covers any disturbance in terms of functional states associated with health conditions at body, individual and society levels (Imrie, 2004). Functional states include body functions and structures, activities at the individual level and participation in society. As the ICF suggests, disability is the variation of human functioning caused by one or a combination of the following: the loss or abnormality of a body part (*i.e.* impairment); difficulties an individual may have in executing activities (*i.e.* activity limitations); and/or problems an individual may experience in involvement in life situations (*i.e.* participation restrictions). The ICF also notes that variations in human functioning (*i.e.* disability) are influenced by contextual factors, including environmental factors or aspects of the external or extrinsic world such as social systems and services, and personal factors, such as age, ethnicity, gender, social status, etc (Imrie, 2004).

Nevertheless, the medical profession works from a biological perspective and this has led to disability being conceived of as merely a biological product (Brittain, 2004). Hence, there is a general view in the population that the problems facing people with disabilities "are the result of their physical and/or mental impairments and are independent of the wider sociocultural, physical, and political environments" (Brittain, 2004, p. 430). The medical profession has power within society, and this has played a significant role in creating many of the societal perceptions of disability that abound within the medical model discourse (Brittain, 2004). As Grönvik (2007) explains:

> Historically, disability has been viewed as the property of the medical sciences. The site of disability has been the body and the efforts to reduce, prohibit, and eliminate disability have focused on the individual. Consequently, the concept of disability has been built upon (bio-) medical vocabulary. Ideas of the *normal body* and its *normal functions* have been the point of departure to identify disabled people…Maintaining the historical perspective, the medical notions of disability have been established and acknowledged for decades (p.761).

Given the (bio-)medical view of disability, and its focus on 'normality', those outside the 'normal range' are deemed as deviant. This social deviance lens is what medical sociologists often theorise chronic illness and disability through (Thomas, 2007). Cockerham (2004) in the ninth edition of his book Medical Sociology explains:

> The basis for describing illness as a form of deviant behaviour lies in the sociological definition of deviance as any act or behaviour that violates the social norms within a given social system. Thus, deviant behaviour is not simply a variation from a statistical average. Instead, a pronouncement of deviant behaviour involves making a social judgement about what is right or proper behaviour according to a social norm…Conformity to prevailing norms is generally rewarded by group acceptance and approval behaviour; deviation from a norm, however, can lead to disapproval of behaviour, punishment, or other forms of social sanctions being applied against the offender. (p 142)

However, in order for the social deviance lens to make sense, one must come to understand the concepts of 'normal' and 'abnormal'. It has been pointed out that "we do not come to understand 'normalcy' through the positive context of its own constitutive elements; we define 'normalcy' by the extensive network of positions that define 'abnormalcy' – those biologies believed to deviate too

dramatically from the norm" (Jarman et al., 2002, p. 567). Corker and Shakespeare (2002) similarly state:

> a Derridean[1] perspective on disability would argue that though they are antagonistic, 'normativism' needs 'disability' for its own definition; a person without an impairment can define him/herself as 'normal' only in opposition to that which s/he is not – a person with an impairment. Disability is not excluded from 'normativism': it is integral to its very assertion (p.7).

In fact, the concepts of norm and average were first coined in the nineteenth century (Hughes, 2000), and were bound up with developments in numerical science: statistics and the concept of the bell curve – the 'normal curve' (Thomas, 2007). In fact, Davis (2002) argues:

> Before the rise of the concept of normalcy…there appears not to have been a concept of the normal, but instead the regnant paradigm was one revolving around the word ideal. If people have a concept of the ideal, then all human beings fall below that standard and so exist in varying degrees of imperfection. The key point is that in a culture of the ideal, physical imperfections are not seen as absolute, but part of a descending continuum from top to bottom. No one, for example, can have an ideal body, and therefore no one has to have an ideal body (p.105).

Based on the concepts of norm, the medical model of disability strives to 'fix' people with impairments, and one prominent way is through rehabilitation (Gilson & Depoy, 2000). In this view, individuals are "defined not only by their diagnosed conditions, but also by the degree to which those conditions are barriers to their function in developmentally normative life roles" (Gilson & Depoy, 2000, p. 208). Therefore, in the modernised world, disability is often related to a person's ability to make economic contributions: "normal" people functionally sustain the economy, family life, and other core fibres of the social organism (Gilson & Depoy, 2000; Thomas, 2007). Thus, illness and disability represents social deviance because ill and disabled people opt out of their productive and contributory social roles; their

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[1] Jacques Derrida (1974) describes the tradition of Western philosophy as relying on a series of binary oppositions (i.e. good/evil, masculine/feminine), with a hierarchy in each binary pair in which the first term is privileged as original and authentic, whereas the second is derivative and subordinate. Derrida's 'general strategy of deconstruction' (1981, p. 41) aims to disrupt these pairs by illustrating the ways in which each of the terms in a binary inhabits and relies upon the other for its own presence and meaning; however, further detail on this perspective are beyond the scope of this paper. For further information, please see the work of Derrida (1974; 1981).

incapacity undermines the social structure (Parsons, 1951). To be impaired is to be perceived as invalid (Hughes, 1999): as Thomas (2007) states:

> Put simply, "everyone knows" that being chronically ill or disabled constitutes '"a trouble"; these are deviant and devalued social states to be avoided at all costs and, if encountered, then remedied if at all possible. But this is to understate the case: being ill or disabled diminishes a person's *competence* – the essential presupposition of membership in society (p.28).

2.1.2.2 Criticisms of the Medical Model

The medical model has held sway in modern society for many reasons. Brittain (2004) summarizes the main reasons:

> the power of the medical profession to define the discourse of disability, the legitimization of this discourse by other groups and institutions within society, economic arguments, fear of difference and lack of understanding, and the use of societal norms combined with a marginalization by members of society of any person or group that does not conform to those norms (p. 435)

However, in recent years many criticisms of the medical model have arisen, which has led activists and academics to use sociological ideas to build a distinct and radical sociology of disability (Abberley, 1987; Barnes & Mercer, 1996; Barnes, Mercer, & Shakespeare, 1999; Barnes, Oliver, & Barton, 2002; Barton, 1996; Finkelstein, 1980; Morris, 1996; Oliver, 1990, 1996a; Thomas, 1999). The main criticisms of the medical model have revolved around: 1) the assumption that disability is a personal tragedy; 2) its focus on fixed, biological bodies; and 3) its lack of social perspectives on disability.

The first criticism of the medical model is the assumption that disability is a personal tragedy. This may stem from the medical model view that disabled people are somehow "lacking" or "unable to play a "full role" in society (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, 2004). This focus on personal tragedy has led disabled activists to argue that the "feelings of inadequacy, self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment" are the result, not of a personal response to tragedy, but of "internalized oppression" (Barnes et al., 1999, p. 178; Galvin, 2005).

A second criticism of the medical model is its focus on fixed, biological bodies. There is a widespread belief that 'disability' and 'being disabled' is *all about*

the body and its defects (Thomas, 2007). As Donoghue (2003) explains, "medical terminology…suggests that the physical limitations of the disabled are what cause people to be discriminative. This stands in stark contrast to the minority group position on disability" (p.203).

Linked to this emphasis on biological bodies, a third criticism of the medical model is its lack of social perspectives on disability. Disability theorists and activists have contended that society has created disability by choosing not to remove structural constraints that would enable more people to participate and gain access to social resources (Donoghue, 2003).

Consequently, the medical model of disability, with its emphasis on individuality, rehabilitation and sense of personal tragedy, has been challenged by the social model which emphasises that many of the disadvantages faced by disabled people arise because of wider society's inability to accommodate them (Corker & French, 1999; Oliver, 1990, 1996b). Donoghue (2003) explains, "by adopting a social constructionist viewpoint, theorists and activists have contended that society has created disability by choosing not to remove structural constraints that would enable more people to participate and gain access to social resources" (p. 204). This challenge meant that disability was no longer conceived as, or reduced to, a deficit body, but re-conceptualised as a product of social organisation or as a consequence of the social relationships of production in a capitalist society (Oliver, 1990). These criticisms have led to a different model for understanding disability, with the formation of the Union of the Physically Impaired Against Segregation (UPIAS).

2.1.3 The Social Model of Disability
2.1.3.1 What is the Social Model?

UPIAS led to the redefinition of disability by making a clear distinction between impairment and disability (Barnes, 1998). According to UPIAS (1976), impairment concerns the biological "lacking part or all of a limb, or having a defective limb, or mechanism of the body", and disability is about the social "disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical

impairments and thus excludes them from participation in the mainstream of social activities" (p.14). This definition was later broadened to accommodate all impairments – physical, sensory, and intellectual – and adopted by other organisations (Barnes, 1998). This definition works on the basis that disability is constituted both by impairments and the disabling environment (Barnes, 1998).

The social model, which arose through the critiques of the medical model and the formation of UPIAS, asserts that disability is not caused by impairment but results from the social restrictions imposed upon people with impairment: "…ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on" (Oliver, 1996b, p. 33). Therefore, in contradiction to the medical model, which views disability through a social deviance lens, the social model instead uses a social oppression lens (Thomas, 2007).

The development of the social model of disability has lead to many benefits for the disabled community. For example, Thomas (2002) argues that the social model of disability has been tremendously important in helping challenge the idea that the problems disabled people face are the inevitable, 'tragic' consequences of having impaired bodies. In addition:

> by drawing attention to economic, social and physical barriers, the social model leads to demands for greater accessibility of buildings, transport, and information, and for measures to counter discrimination in employment and other spheres of activity (Burchardt, 2004, p. 736).

Overall then, "the social approach to disability…has played a crucial role in the development of the disability movement and the ongoing political struggle of disability rights" (Huang & Brittain, 2006, p. 354). It has helped challenge conventional characterizations of the disabled as abnormal, inferior, or dependent people who at best should be pitied or treated as objects of charitable goodwill (Berger, 2008). As Thomas (2008) explains:

> 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. This 'problem and solution' perspective has fuelled the British disabled people's movement's political programme and informed the research agenda in disability studies

for the past three decades. Many would agree that the results have been very impressive, albeit partial and incomplete – for example, anti-discrimination legislation in the form of the Disability Discrimination Act (1995, 2005), "direct payments" arrangements and widespread attitudinal change in favour of inclusion (Thomas, 2008, p. 15)

Shakespeare (2006) similarly reviews the benefits the social model has accrued for the disabled community:

> The benefits of the social model approach are that it shifts attention from individuals and their physical or mental deficits to the ways in which society includes or excludes them. The social model is social constructionist…rather than reductionist or biologically determinist. Rather than essentialising disability, it signals that the experience of disabled people is dependent on social context…Rather than disability being inescapable, it becomes a product of social arrangements, and can thus be reduced, or possibly even eliminated…The social model was crucial to the British disability movement for two reasons. First, it identified a political strategy: barrier removal. If people with impairments are disabled by society, then the priority is to dismantle these disabling barriers, in order to promote the inclusion of people with impairments. Rather than pursuing a strategy of cure or rehabilitation, it is better to pursue a strategy of social transformation…The second impact of the social model was on disabled people themselves. Replacing a traditional deficit approach with a social oppression understanding was, and remains, very liberating for disabled individuals. Suddenly, people were able to understand that it was society which was at fault, not themselves. They didn't need to change: society needed to change. They didn't have to be sorry for themselves; rather, they could be angry… Given that, in Britain, disability rights and disability studies have up to this point been inseparable from the social model concept, then clearly credit has to be paid to the mobilising power and strategic impact of the social model redefinition of disability. Activists created the social model, which inspired new generations of activists, who fought for the structural changes which the social model mandated (Shakespeare, 2006, pp. 29-31)

2.1.3.2 Criticisms of the Social Model

Recently, despite the many benefits it may have, there have been a number of critiques of the social model due to certain problems inherent in its definition of disability. These problems revolve around: 1) impairment and the body; 2) model vs. theory; 3) lived experience; and 4) psycho-emotional disability.

The first criticism of the social model is that, in its eagerness to move away from the medical model of disability, the social model completely ignores the issue of impairment. It has been argued by Hughes and Paterson (1997) that confining impairment to the domain of nature (which medical discourse claims as its object)

is to accept, without question, medical jurisdiction over matters of the body and to concede apolitical, medical agenda with respect to it. As they go on to explain:

> with respect to the body and impairment, the social model makes no concession to constructionism or epistemological relativism: it posits a body devoid of history. It also posits a body devoid of meaning, a dysfunctional, anatomical, corporeal mass…without intentionality or agency…[T]here is a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self (Hughes & Paterson, 1997, p. 329).

Thus, as Hughes (1999) points out

> the structuralist emphasis of the social model of disability leaves it poorly placed to develop a sociological analysis of impairment of the body. It is also dualistic, since it draws a clear distinction between nature and the social, with impairment consigned to the former domain and disability to the latter" (p.160).

Hughes (1999) further comments:

> The connection between impairment and oppression is lost to the social model of disability because impairment is regarded as something that is constituted entirely in the domain of nature and is, therefore, a natural fact beyond contestation. In other words, the social model concedes that impairment is a disfigurement and therefore accepts the medico-aesthetic distinction between valid and invalid bodies. This position actually adds legitimacy to accounts of impairment that are shaped by notions of tragedy and pity. Such a position hinders the theoretical and practical basis for politics of pride and difference. (p.68)

A second criticism of the social model relates to Oliver's (1996b) caution that "the social model of disability is […] not a substitute for social theory, a materialist history of disability, nor an explanation of the welfare state" (p. 41). In Finkelstein's (2001) words: "sadly, a lot of people have come to think of the social model of disability as if it were an explanation, definition or theory, and many people use the model in a rather formalistic way" (p.6). This formalistic view has been adopted by advocates of the social model and has lead to it, until recently, becoming stagnated rather than built upon and improved.

A third criticism of the social model revolves around the lived experience of disability. Within the social model, lived experience becomes 'washed out' as only the social aspects of disability are explored. This, in combination with the absence of the body in the social model, means that much of what people with impairments deal with in everyday is left unexplored. As Crow (1996) explains:

we have tended to centre on disability as 'all'. Sometimes it feels as if this focus is so absolute that we are in danger of assuming that impairment has no part at all in determining our experiences (p. 57).

It has also been pointed out that the focus of the social model has been on the 'public' experiences of oppression such as social barriers, at the expense of the more 'personal' experiences of oppression which operate at the emotional level (Thomas, 1999). This emphasis upon the social environment has tended to direct attention away from the individual which ultimately has implication for the lives of disabled people, since key areas of research concerning important aspects of their lives are not enquired into (Edwards, 2008).

A fourth criticism of the social model is proposed by Thomas (1999), namely the "psycho-emotional dimensions of disability". She states: "psycho-emotional disablism involves the intended or unintended 'hurtful' words and social actions of non-disabled people in inter-personal engagement with people with impairments" (Thomas, 2007, p. 72). This particular dimension of disability has previously been ignored by both the medical and social models of disability.

2.1.2.3 Where do we go from here?

These criticisms of the social model have the possibility of leading us in various directions. Carol Thomas, who advocates a possible redefinition of the social model, exemplifies one possible standpoint. Firstly, Thomas (2004) believes that a separation should be made between impairment and what she calls 'impairment effects'. According to Thomas (2007),

> impairment effects refer to those restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations designated 'impairments' rather than to those *imposed upon* people *because* they have designated impairments (disablism) (p.136).

In Thomas' (2004) mind:

> what has been lost is an understanding that disability *only* comes into play when the restrictions of activity experienced by people with impairment are *socially imposed*, that is, when they are wholly social in origin. Such a social relational view means that it is entirely possible to acknowledge that impairments and chronic illness directly cause *some* restrictions of activity. The point is that such non-socially imposed restrictions of activity do not constitute 'disability'. Such non-socially imposed restrictions might be better captured by the concept 'impairment effects' (p.580).

Gleeson (1997) feels similarly: "Far from being a natural human experience, disability is what *may* become of impairment as each society produces itself sociospatially: there is no *necessary* correspondence between impairment and disability" (p.194).

In addition, Thomas (2004) feels that psycho-emotional disablism significantly affects disabled people in their everyday lives. She states:

> Social barriers 'out there' certainly place limits on what disabled people *can do*, but psycho-emotional disablism places limits on who they *can be* by shaping individuals' 'inner worlds', 'sense of self' and social behaviours" (Thomas, 2007, p. 72).

In order to bring these ideas into social model research, Thomas (1999) proposes a redefinition of disability within the social model:

> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being (Thomas, 1999, p. 60)

Shakespeare and Watson (2001), who advocate an outright rejection of the social model, exemplify another possible standpoint. They argue:

> People are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial. The British social model approach, because it 'over-eggs the pudding', risks discrediting the entire dish (Shakespeare & Watson, 2001, p. 17)

There are a number of reasons that a rejection of the social model has been proposed. Shakespeare (2006) goes into great detail for his reasoning to reject the social model in his book, 'Disability Rights and Wrongs'. In summary, one of the main reasons Shakespeare believes the social model should be scrapped altogether is the "strong opposition from within the British disability community" (Shakespeare, 2006, p. 39) to previous calls for reform or development of the model. He states:

> alone amongst radical movements, the UK disability rights tradition has, like a fundamentalist religion, retained its allegiance to a narrow reading of its founding assumptions" (Shakespeare, 2006, pp. 33-34)

In his view, "the strength and simplicity of the social model has created as many problems as it has solved" (Shakespeare, 2006, p. 31). He believes that the distinction made in the separation of disability and impairment has oversimplified a

complicated interaction, and since this distinction lies at the heart of the social model, it causes the model itself to be flawed. He explains, "the inextricable interconnection of impairment and disability is demonstrated by the difficulty in understanding, in particular examples, where the distinction between the two aspects of disabled people's experience lies. While theoretically or politically it may appear simple to distinguish impairment from disability, qualitative research has found it very difficult to operationalise the social model because it is hard to separate impairment from disability in the everyday lives of disabled people (Shakespeare, 2006, p. 36). Shakespeare would instead prefer to use the term 'disability' as a broader term to "describe the whole interplay of different factors which make up the experience of people with impairments" (Shakespeare, 2006, p. 58).

Shakespeare is also unhappy that the social model of disability has become

…a kind of litmus test, by which disability activists assess interventions. If an initiative or organisation appears to contradict the social model, it must be rejected as inappropriate, misguided or even oppressive. The simplest form of this 'disability correctness' arises from basic terminology: the social model mandates the term 'disabled people' because people with impairment are disabled by society not their bodies. The phrase 'people with disabilities' becomes unacceptable because it implies that 'disabilities' are individual deficits. Those who refer to 'people with disabilities' are thus adopting the 'medical model' and must be re-educated or repudiated (Shakespeare, 2006, p. 32)

Shakespeare believes that

the weaknesses of the British approach now outweigh the benefits. Translation of ideas and ideologies from activism to academia has not been accompanied by a sufficient process of self-criticism, testing, and empirical verification. The social model of disability which has successfully inspired generations of activists has largely failed to produce good empirical research, because it relies on an overly narrow and flawed conception of disability (Shakespeare, 2006, p. 9).

He later continues:

Disability studies would be better off without the social model, which has become fatally undermined by its own contradictions and inadequacies. To reject the British social model does not mean returning to the bad old days of medicalisation and individualist approaches before the UPIAS revolution. There are many other, more robust, ways of conceptualising disability, which retain a commitment to equality and justice for disabled people, but do not base the analysis on a mistaken bracketing of bodily differences (Shakespeare, 2006, p. 28)

However, although the two main directions advocated for moving on from the social model appear wholly different, both Thomas and Shakespeare agree that their views are "not, on the surface of things, a million miles apart: that disabled individuals live lives shaped both by impairment effects and by the effects of disablist social factors" (Thomas, 2008, p. 41). Indeed, Thomas and Shakespeare "both agree that a *relational approach* to understanding disability is needed. By relational, [Shakespeare] means that the disability is a relationship between intrinsic factors (impairments etc) and extrinsic factors (environments, support systems, oppression etc)." (Shakespeare, 2006, p. 57, italics added). Indeed, a number of authors have made similar statements, including Imrie (2004) who states that

> physical and mental impairment, in contributing to functional limitations of bodies, cannot be discounted as ephemeral in the construction of disability and disabled people's lives. Rather, a focus on *interaction* between functionally impaired bodies and socio-cultural relations and processes is seen, by some, as crucial in the development of a non-reductive and non-essentialised understanding of disability" (Imrie, 2004, p. 288, italics added).

However, Shakespeare disagrees that this relational approach can be fully understood from within a social model perspective. He explains:

> for some individuals impairment is a major limiting factor, which renders any social manipulation or barrier removal almost irrelevant. For others, impairment itself causes little restriction: it is the reaction of others which causes problems of exclusion and disadvantage. The interactional model can allow for this variation" (Shakespeare, 2006, p. 60).

As we can see, the definition of the term 'disability' is still being hotly debated. My point here is not to settle these debates, but to signal that there are various ways in which we might define disability. Also, it is important to note here that the disagreements revolve around a central theme of this thesis; that is, the body. For example, as noted earlier, a main disagreement between understandings of disability comes down to whether there should continue be a distinction made between 'disability' and 'impairment', and whether those terms can be as neatly separated as they have been within the social model. The entire social model rests on the distinction between disability and impairment; therefore, how one chooses

to define disability in many ways determines where we go from the social model: (1) development and reform; or (2) rejection.

However, the definition of disability is also affected by how we position the body within the disability debate. The main topic here is the question of how to bring the body back into the theorising of disability, without opening up to a re-medicalisation of disability (Grönvik, 2007). Engagement between disability studies and the sociology of the body is confounded by theoretical and political tensions (Paterson & Hughes, 1999).

> Disability studies made its way into the academy on the basis of its opposition to the idea, deeply rooted both within and outside social science disciplines, that 'disability' and 'being disabled' is *all about* the body and its deficits…from this perspective, any focus on impairment or 'the body' conceded ground to the biological reductionism that had been orchestrated and sustained by doctors and other health and social care professionals for more than two centuries…in this context it was seemed diversionary and wasteful of resources to spend disciplinary time and energy examining the impaired body (Thomas, 2007, p. 121)

2.2 The Body

2.2.1 What is it?

In order to understand the position of the body and its relation to disability, we must first understand what 'the body' is and why it is important. Once again, this is not as simple to describe as it would seem. As Turner (1994, p. 46) explains:

> For Poststructuralism, the body is 'the body', an abstract, singular, intrinsically self-existing and socially unconnected, individual; the social behaviour, personal identity and cultural meaning of this entity are passively determined by (disembodied) authorative discourses of power. For the new political movements of personal-social, cultural-environmental resistance, by contrast, 'the body' consists essentially in processes of self-productive activity, at once subjective and objective, meaningful and material, personal and social, an agent that produces discourses as well as receiving them.

Understanding what 'the body' encompasses is important for many reasons, but especially because

> it is our bodies which allow us to act, to intervene in, and to alter the flow of daily life. Indeed, it is impossible to have an adequate theory of human agency without taking into account the body. In a very important sense acting people are acting bodies" (Shilling, 2003, p. 8).

According to Moss & Dyck (2002),

> materially, our bodies circumscribe our existences. In this sense we are sensual beings, ones that are tactile, emotional and sensorial…at the same

time, our bodies carry cultural markers that tag us as aged, raced, sexed, classed, sexualised, disabled and ill (p. 67).

Many believe "the lived body is not just one thing in the world, but a way in which the world comes to be" (Leder, 1992, p. 25). "The body" is an important topic to research because:

> Our lives, including our health, hinge on our bodies; we depend on them; engage the world and the people around us with them; live in them and through them; do things with and to them; exist as and for them; experience having them and being them; feel them; and are them. In effect, then, the body is implicated in everything people do, and thus demands attention (Smith & Sparkes, 2007, p. 27)

According to Husserl (1969), the body is "the medium of all perception" (p. 61), and it is through the body that people gain access to the world (Lyon & Barbelet, 1994). Within the German language, this is portrayed via the two separate words meaning 'body': "Korper" and "Leib". The notion of a leib and korper interpretation of embodiment originates in works in phenomenology and physical anthropology (Gehlen, 1988; Merleau-Ponty, 1962; Overboe, 1999). A korper interpretation of the body reduces it to a classification, whereas a leib interpretation considers the body to be an entity which experiences itself and its environment (Leder, 1990). According to Leder (1990), since the time of Descartes people have interpreted the body as korper rather than leib, which has resulted in a rationalization that views the physical body only as an object to be classified like any other thing. As Bendelow & Williams (1995) explain:

> Human beings…have a dual nature; one which is succinctly captured in the German language by the terms Leib, which refers to animated living through the experiential body (ie. the body-for-itself) and Korper, which refers to the objective, exterior, institutionalized body (ie the body-in-itself)…[This] expresses the essential ambiguity of human embodiment as both personal and impersonal, objective and subjective, social and natural. Moreover, it serves to highlight the weakness of the Cartesian legacy for sociology which has resulted in an almost exclusive representation of the body as Korper rather than simultaneously as Korper and Leib. (p. 147).

Traditional theories of the body can be organised into two major standpoints: as either essentialist (material) or nonessentialist (discursive) orientations (Chau et al., 2008). An essentialist orientation of the body views it as a stable, homogenous, and objective physical entity. A nonessentialist orientation views the body as dynamic, heterogenous, and nonmaterial or socially constructed. Much critique of

both these polar orientations has led to many scholars synthesizing the two approaches to view the body as both material and discursive (Moss & Dyck, 2002). Jackson and Scott (2001) explain that sociologists began to pay attention to the body due to a:

> realisation that social interaction is facilitated by bodily negotiations; that we recognize others through their bodies, that we categorize them by age, gender, ethnicity – even class – through bodily attributes; that this recognition itself requires a set of cultural competencies through which we read the significance of dress, demeanour and deportment" (pp. 9-10).

However, it has been noted that the sociology of the body:

> is characterised by an abundance of theorizing, but a systematic empirical research tradition is lacking…Research on the body has been chastised for privileging theorizing, of bracketing our the individual, and for ignoring the practical experiences of embodiment (Wainwright & Turner, 2006, p. 238)

For various reasons, 'the body' remains one of the most contested concepts in the social sciences (Shilling, 2007). In many ways, "the more we focus on the body, the more we lose sight of the context; when the context comes into focus, the body fades from view" (Jackson & Scott, 2001, p. 10). In recent years, further attention has been brought to the study of the body, as more people begin to realise that:

> order begins with the body, and our understanding of ourselves and our world begins with our reliance on the orderly functioning of our bodies. This bodily knowledge informs what we say and do in the course of our daily life. We carry our histories with us into the present through our bodies. The past is 'sedimented' in the body; that is, it is embodied (Becker, 1999, p. 12)

In addition, Shilling (1993) has come to understand that "in the affluent West, there is a tendency for the body to be seen as an entity which is in the process of becoming: a *project* which should be worked at and accomplished as part of an *individual's* self identity" (p. 4-5, emphasis in original). Finally, it has become clear in recent years that the body is at the heart of the social self, and that its constitution is both biological and cultural (Hughes, 2000); therefore, it is felt that it should be possible to understand the 'impaired body' as simultaneously biological, material and social – in short, bio-social in character (Imrie, 2004; Thomas, 2007).

2.2.2 Embodiment

In order to discuss embodiment further, we must first understand what is meant by the term 'embodiment' and how it differs from 'the body'. According to Cregan (2006):

> Embodiment – the physical and mental experience of existence – is the condition of possibility for our relating to other people and to the world. Fully able or seriously disabled, it is through our physicality that we function as social beings, whether in face-to-face communications, through hand-written letters, printed missives, or by keying disembodied electronic symbols into a computer to 'stay in touch' with someone half a world away. Embodied social relations exists both as the content (the prior circumstances) and as an outcome (a consequence) of given social formations, given systems through which we create and gain social meaning (Cregan, 2006, p. 3)

> Embodied sociology, according to Williams & Bendelow (1998), involves:

> theorizing not so much *about* bodies (in a largely disembodied male way) but *from* bodies as *lived* entities, including those of its practitioners as well as its subjects. Social institutions and discursive practices cannot be understood apart from the real lived experiences and actions of embodied human beings across time and space. Social theory must therefore be rooted in the problems of human embodiment (p. 209).

Indeed, Shilling (2001) has found that a number of authors

> analyse human embodiment as a distinctive phenomenon which is outside the exclusive control of society, yet which nevertheless provides a crucial link between individuals and the social milieu in which they live (p.332).

Unfortunately, while embodiment is recognised as significant, it is generally analysed only in terms of its ties to and interdependence with other phenomena (Shilling, 2007).

During the last decade 'there has been an outpouring of literature on the importance of embodiment and the body as central issues for the humanities and social sciences' (Featherstone & Turner, 1995, p. 2). Despite this concern with the body, general interpretations of sociology tended to marginalise the significance of embodiment to social life (Shilling, 2007). This is due to the fact that:

> If anything defines sociology as a discipline distinct from other modern disciplines, it is the pervasive and persistent tensions between structure and agency. The relative weight and value accorded to *either* structure *or* agency have characterized the development of the various schools of thought and practice associated with Western sociology (Howson, 2005, p. 16)

Therefore, body theorists have had to choose between this criterion of 'classic sociology' (apparently condemned to view the body as an object, and thus not perceived as a source of personal knowledge or understanding, nor deemed relevant to the production of sociological knowledge) or the more eclectic and flexible resources provided by cultural studies (supposedly more able to account for the body as lived and less likely to structurally erase the embodied subject) (Howson & Inglis, 2001). However, it has been pointed out that even if classical sociological conceptions of embodied experience are judged to be incomplete, this provides sociologists of the body with a prime opportunity to return to their heritage and to develop with the assistance of other resources, rather than simply abandon, the sociological tradition (Shilling, 2001). In addition to tracing the position of the body in sociology, contemporary sociologists have sought to utilise resources previously classified as being at the margins of, or outside, the discipline (Shilling, 2001).

Just as there were many lenses through which one could look at disability, so it is with the body and embodiment. A few of these lenses include: biology, narrative and phenomenology. As has already been mentioned, many researchers are moving away from a solely biological perspective towards the body, as this is seen as much too simplistic a notion. One of the main narrative theorists on the body is Arthur Frank (1995). According to Frank (1995) there are four ideal typical bodies, and these typical bodies are created as the body faces four problems of embodiment and defines itself within the four continua of responses (Frank, 1995).

Figure 1. Body Problems (Frank, 1995)
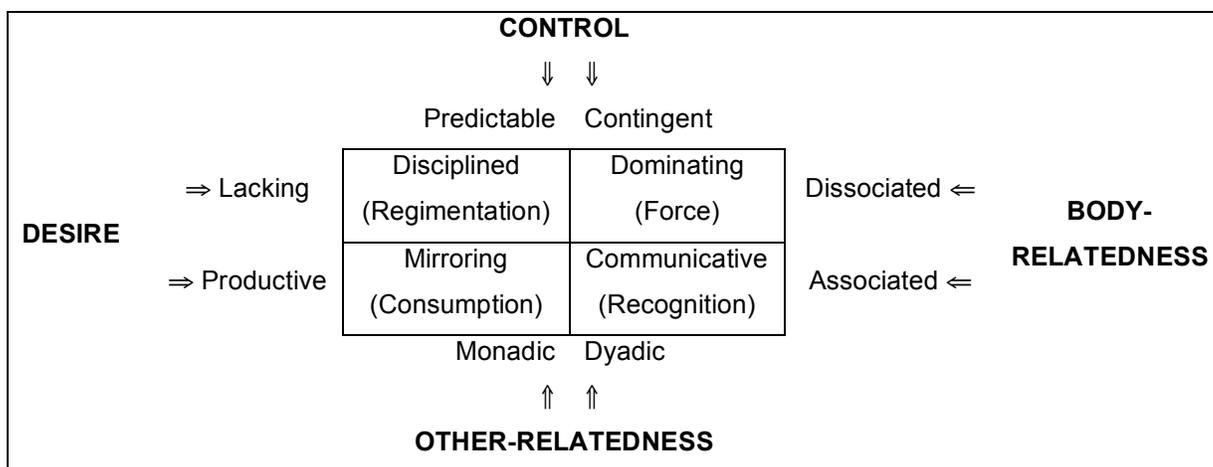
However, it must be noted that "this language is an imposition on bodies; real people are not ideal types…actual body-selves represent distinctive mixtures of ideal types" (Frank, 1995, p. 29). The four general problems of embodiment are: control, body-relatedness, other-relatedness, and desire. The four ideal bodies are the disciplined body, the mirroring body, the dominating body and the communicative body, and they define themselves in the following way:

> Disciplined body: defines itself primarily in actions of self-regimentation that make itself predictable. It experiences its most serious crisis in loss of control. Desire is lacking. Other relatedness is monadic. In terms of self-relatedness it is dissociated from itself.
> Mirroring body: defines itself in acts of consumption. It remains predictable as it reflects that which is around it. It attempts to recreate the body in images of other bodies: more stylish and healthier bodies. Other relatedness remains monadic. Via consumption it is endlessly producing desires. It is associated with its own surface.
> Dominating body: defines itself in force. Tends to be male bodies. Characterized by a sense of lack, anxiety and fear. Thus, this body's response to its sense of its own contingency, its dissociated self-relatedness and its dyadic other-relatedness, are all configured by lack. Although dyadic in its other-relatedness, it is against others rather than for others.
> Communicative body: is an idealized body in the process of creating itself. The body's contingency is no longer its problem but its possibility. Other-relatedness is dyadic. This desire for dyadic expression and sharing is producing. In terms of self-relatedness it is associated with itself. (Frank, 1995, pp. 40-52)

Frank (1995) also uses another lens through which one can examine the body and embodiment: phenomenology. Phenomenology of the body or 'embodiment' is particularly important in that it provides sociologists with a sensitive and sophisticated perspective on issues such as pain, disability and death (Paterson & Hughes, 1999). This lens emphasizes the mind-body nexus, and its focus upon the 'here and now of bodily existence and presence' (Münch, 1994, p. 151) acknowledges the centrality of the body in the relationship between self-consciousness and the self (Hockey & Allen-Collinson, 2007). Merleau-Ponty (1962) understood human perception and 'being' to be an embodied phenomenon: our access to the world and to meaning is by way of our perceiving bodies. From this standpoint, the body is not so much an instrument nor an object, but rather the subject of perception, socially and indeed sub-culturally mediated though that perception may be (Hockey & Allen-Collinson, 2007). Meaning resides in the body,

and the body is seen to reside in the world (Merleau-Ponty, 1962). As we will come to see, the body, and embodied experience, is important to those people living in impaired bodies.

2.2.3 Body, Embodiment and Disability

Within disability studies, the term 'body' tends to be used without much sense of bodily-ness as if the body were little more than flesh and bones (Paterson & Hughes, 1999). Such tendencies miss 'the opportunity to add sentience and sensibility to our notions of self and person, and to insert an added dimension of materiality to our notions of culture and history' (Csordas, 1994, p. 4). In addition, it fails to realise that:

> The impaired body is a 'lived body'. Disabled people experience impairment, as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction. The body is the stuff of human affliction and affectivity as well as the subject/object of oppression. The value of a phenomenological sociology of the body to the development of a sociology of impairment is that it embodies the addition of sentience and sensibility to the notions of oppression and exclusion. 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 (Hughes & Paterson, 1997, pp. 334 - 335)

One of the many reasons that disability is believed to be a bio-social phenomenon is explained by Thomas (2002), who states:

> Somehow, bodies need to be theorized as, at the same time, bio-socially produced and culturally constructed entities. Both biological reductionism and cultural reductionism need to be avoided. Significant impairments need to be seen as real differences from the 'usual' body whilst simultaneously understood to be invested with meanings or representations that construct these differences in the socio-medical language of 'impairment', 'disfigurement', and so forth. In addition, we need to work on an understanding of the way in which the biological reality of bodies is shaped by, and impacts back upon, social and environmental processes and practices: that is, on the ways in which bodies are the effects of bio-social interaction (p.76)

It is believed that a sociology of impairment that is phenomenological would facilitate the scholarly task of illustrating that the impaired body has a history and is as much a cultural phenomenon as it is a biological entity (Paterson & Hughes, 1999). This sociology of impairment has been called for because it is undeniable

that impairment plays a part in determining a person's sense of self, because unlike other bodies marked by difference (e.g. race, gender and sexual orientation) disabled people cannot argue that their bodies are not physiologically different from other bodies (Crow, 1996; Promis, Erevelles, & Matthews, 2001). Turner & Wainwright (2003) argue that:

> One should distinguish between the epistemological construction of the body, the ontology of embodiment and the phenomenology of embodiment…'the disabled body', for example, might involve analysis of the rise of the 'disability business' and the political and economic role of stigmatic labels, but 'the embodiment of impairment' invokes a different research agenda, namely the study of the everyday world of impairment. One can recognise the political importance of the notion that disability is socially constructed without rejecting the equally important task of understanding the phenomenology of impairment and the experiences of disability in terms of social ontology (p. 277).

In the study of impairment and disability, the term 'impairment effects' has recently come into usage through the work of Thomas (2007). For example, a woman with a spinal cord injury has a physical impairment. If this woman is unable to gain access to a public building because there is no elevator or wheelchair ramp, it is considered a disability, and thus a form of social oppression. However, this deprivation of opportunities will not disappear simply by the removal of all disablist and disabling socio-structural barriers (Smith & Sparkes, 2008a) because she also has impairment effects: restrictions directly associated with having a physical impairment and being a material body that is unable to do certain things. Therefore, she experiences pain and tiredness, bowel and bladder problems, and may be unable to physically cuddle her children. Hence, "in any 'real' social setting, impairments, impairment effects and disablism are thoroughly intermeshed with the social conditions that bring them into being and give them meaning" (Thomas, 2007, p. 137). Indeed, even the World Health Organisation has come to recognise the bio-social nature of disability; the International Classification of Functioning, Disability and Health is "based on the biopsychosocial model of disability, which is an integration of the medical and social models. ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual and social" (WHO, 2002).

Impairment and its effects are at one and the same time of the body, or embodied, and socially contingent in a materialist sense – the embodied act is thus bio-social (Thomas, 2007); it is this biological and social quality that makes the body at once such an obvious, and yet such an elusive phenomenon (Shilling, 2003). Embodiment is a social, as well as a biological, phenomenon because people with disabilities "are looked upon, identified, judged and represented primarily through their bodies, which are perceived in popular consciousness to be imperfect, incomplete and inadequate" (Hargreaves, 2000, p. 185).

Given this emphasis, and calls for a focus on the body when exploring disabled people's lives, how might we begin to understand 'the body'? One way is through narrative. As Frank (1995) states:

> The body is not mute, but it is inarticulate; it does not use speech, yet begets it. The speech that the body begets includes illness stories; the problem of hearing these stories is to hear the body speaking in them. People telling illness stories do not simply describe their sick bodies; their bodies give their stories their particular shape and direction. People certainly talk about their bodies in illness stories; what is harder to hear in the story is the body creating the person (p. 27)

Indeed, "the act of narration that structures and projects our sense of selfhood and identity over time, along with the tellability of personal stories, is an embodied process" (Smith & Sparkes, 2008a, p. 219). In the following section, I will discuss stories and narrative, and how it is helpful in researching the body, embodiment and disability.

2.3 Narrative

2.3.1 What is it?

In the simplest terms, a narrative is a story; it has a plotline, with a beginning, middle and an end. According to Hendry (2007), "stories are what makes us human. Our narratives, be they life stories, autobiographies, histories, sciences, or literature are the tales through which we constitute our identities. We are our narratives" (p. 495). However, narrative is also much more than that; as Turner (1987) explains:

> Scientific knowledge of the world is a form of narrative (a story) and like all narratives science depends on various conventions of language (a style of writing, for instance). Narrative is a set of events within a language and

language is a self-referential system. Nothing occurs outside language. Therefore, what we know about 'the world' is simply the outcome of arbitrary convention we adopt to describe the world. Different societies and different historical periods have different conventions and therefore different realities (pp. 10-11)

On the other hand, some authors differentiate between a narrative and a story; a Narrative is taken to mean:

a dynamic structure or template embedded in society that has 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. It is a construction which people rely on to tell stories (Smith & Sparkes, 2008b, p. 5).

However, a Story is:

an actual…tale an individual or group tells and performs. It is a verbal or non-verbal act of telling that is the work of a human agent embedded in a social world, and the process of storytelling is something they do or perform to transmit a message (Smith & Sparkes, 2008b).

Thus, the term story is used when referring to actual tales people tell, while narrative is used when discussing general dimensions or properties, such as tellability, consequences, sequences of speech, act, structures, categorical content, rhetorical tropes, and/or temporality, which comprise particular stories (Smith & Sparkes, 2008b); however, they do acknowledge that "since narratives only exist in particular stories, and all stories are narratives, the distinction is hard to sustain" (Frank, 1995, p. 188).

Recent research has suggested that narrative lay knowledge acts as the "medium through which people locate themselves within the places they inhabit and determine how to act within and upon them" (Popay, Williams, Thomas, & Gatrell, 1998, p. 619). According to Polkinghorne (1988) narrative is the "primary scheme by means of which human existence is rendered meaningful…People are story telling organisms who, individually and socially, lead storied lives" (pp. 5, 7). In addition, it is felt that "cultures provide prefabricated narratives for hooking up events of our lives…as agents of our own construction, we chose among available narratives, and sometimes seek stories that transgress the culturally condoned ones" (Richardson, 1997, p. 181). These 'prefabricated narratives' are what Frank, (1995) describes as 'narrative types':

A narrative type is the most general storyline that can be recognised underlying the plot and tensions of particular stories. People tell their own unique stories, but they compose these stories by adapting and combining narrative types that culture makes available (p. 75).

Also emphasising the socio-cultural aspect of narrative, McAdams (2006) comments:

Culture provides people with a menu of narrative forms and contents from which the person selectively draws in an effort to line up lived experience with the kinds of stories available to organize and express it. Indeed, the story menu goes so far as to shape lived experience itself: we live in and through stories. [S]tories are made and remade, performed and edited, instantiated, contoured and lived out in the social ecology of everyday life and with respect to the norms of narrative content, structure, and expression that prevail in a given culture (p. 16)

Not only might narrative shed light on how socio-cultural factors shape our lives, but moreover, according to Eisner (1981), narrative research is important because "it is to the artistic to which we must turn, not as a rejection of the scientific, but because with both we can achieve binocular vision. Looking through one eye never did provide much depth of field" (p. 9). Narrative research "emphasizes personal stories and narratives, the intensely individual nature of each person's experience and people constantly remaking themselves as an active, ongoing social project" (Dhunpath, 2000, p. 545). It also highlights the ways in which our culture and society shape and are shaped by individual lives (Hendry, 2007). Georgakopoulou (2006) explains that even if life is not accepted to be narratively structured, the process of narrativizing it is invariably thought of as involving meaning making, ordering and structuring of the experience.

2.3.2 Narrative, Disability and the Body

Narrative theory is increasingly employed to understand the subjective experience of illness and disability (McLeod, 2000). Frank (1995) argued that people with serious medical conditions make sense of their lives by telling illness stories through their diseased bodies; thus, in an embodied sense, they give voice to an experience medicine cannot describe. In fact, McAdams (1993) believes that the maintenance of a coherent narrative thread provides a sense of meaning and purpose to one's life, and Crossley (2000) theorises that creating and telling stories

of one's life is a necessary part of developing and maintaining a coherent identity and sense of self because it is "through narrative [that] we define who we are, who we were and where we may be in the future" (p. 67). However, Couser (1997) believes that:

> pure illness narratives tend to disengage the body from the self in the way that medical discourse often tends to do. Full life-writing is facilitated, authorised or even required when one assumes that what happens to one's body happens to one's life (p.14)

Frank (2005) suggests three underlying narratives of illness: restitution, chaos and quest narratives; however, he stresses that actual tellings combine all three. The restitution narrative is the most common narrative type, and has the plot: "yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995, p. 77). In disability terms, this becomes: "yesterday I was able-bodied, today I'm disabled, but tomorrow I'll be able-bodied again". This narrative reflects a modernist expectation that for every suffering there is a remedy, and the disabled person's own desire for restitution is often compounded by the expectation that other people want to hear restitution stories (Whitehead, 2006). The chaos narrative is the opposite of restitution: its plot "imagines life never getting better" (Frank, 1995, p. 97). Finally, the quest narrative meets suffering head on; these stories accept contingency and seek to use it (Frank, 1995). Illness, or disability, is the occasion of a journey that becomes a quest; while what is quested for may never be wholly clear, the quest is defined by the person's belief that something is to be gained from the experience (Frank, 1995, p. 115). Each of these narratives reflects strong cultural and personal preferences, and the strength of these preferences present a further barrier to listening to the ill: both institutions and individual listeners steer people toward certain narratives, and other narratives are simply not heard (Frank, 1995, p. 77). Frank (1995) explains:

> The ill body's articulation in stories is a personal task, but the stories told by the ill are also social. The obvious social aspect of stories is that they are told to someone, whether that other person is immediately present or not…From their families and friends, from the popular culture that surrounds them, and from the stories of other ill people, storytellers have learned the formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell. Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others' stories (p.3)

However, it is felt that individuals experiencing chronic illness or disability need alternative narrative resources by which to story their lives in order to prevent narrative wreckage, and thereby preserve or reinstate sense of self, identity, and mental health (Carless & Douglas, 2007; Frank, 1995; Smith & Sparkes, 2005b). This is important because, according to Sparkes and Smith (2002), narrative plays an important role in the construction of identities and selves:

> The stories we are told, and the stories we learn to tell about ourselves and our bodies, are important in terms of how we come to impose order on our embodied experiences and make sense of events and actions in our lives. As individuals construct past events and actions in personal narratives, they engage in a dynamic process of claiming identities, selves and constructing lives. (p.261)

2.4 Identity

2.4.1 What is it?

Identity, like disability, the body, and narrative, is not as simple a concept to explain as it may appear. According to Scott-Hill (2004):

> Identity is concerned with the social formation of the person, the cultural interpretation of the body and the creation and use of markers of membership such as rites of passage and social categories. As such, it might be thought of as mediating between the personal, private world of everyday life and the collective space of multiple cultural forms and social relations: it is a pivot between the social and the individual…identity is social: it is constructed in and through social relations of difference. However, both 'social relations' and 'difference' can be conceptualised in various ways, with the result that 'identity' is not uniform in its meaning (p.87)

Jenkins (1996) also supports the view that identities are social products when he contends that identities are formed in a dialectical relationship between internal factors (i.e., what we think our identities are) and external factors (i.e., how others see us and react to us), which may strengthen or contradict each other.

Hall (1996) has suggested that within the social sciences there are two historical and strategic approaches to the production of identities; however, this is only one rather simplistic perspective, and there are many others. Nevertheless, for Hall (1996), one approach is "based on the assumption that there is an essential, natural or intrinsic meaning to any identity; this identity is based on either a shared social experience, origin or structure" (Watson, 2002, p. 509). The second

approach "denies the existence of any identity based on a shared origin or experience – identities exist only as opposites, they are multiple and temporal" (Watson, 2002, p. 509). According to Watson (2002), much of the writing on disability from within disability studies falls within the first approach; however, it has been questioned whether a 'disabled identity' based on these shared characteristics actually exists. Although identity as a disabled person is often presented as something fixed or stable (Huang & Brittain, 2006), Shakespeare (1996) suggests that it may be necessary to consider a variety of disability identities rather than a single essentialist disability identity. Watson (2002) questions:

> Do disabled people know who they are because of the fact that they have an impairment, because of the fact that they face discrimination or because of who they, ontologically, believe themselves to be? These are fundamental questions in any analysis of disability (p. 512)

Indeed, Giddens (1991) believes that group membership is no longer synonymous with identity formation; he argues that we are able to choose our identity, and can ignore or reject identities fostered on us as a result of ascribed characteristics.

Charmaz (1987) has provided much insight into the fundamental loss of self that accompanies chronic illness. It has been demonstrated that chronic illness with impairment can intrude on a person's daily life, undermine a person's sense of self, and initate various identity dilemmas (Charmaz, 1987; Sparkes, 1998a). Similarly, acute illness with impairment as a form of "biographical disruption[2]" (Bury, 1982) can also set in motion a chain of events that results in the same consequences for an individual (Sparkes, 1998a), which has led to the frequent use of Charmaz' (1987) theories in relation to disability as well as chronic illness.

2.4.2 Identity, the Self and Disability

The ability to recreate a stable identity following chronic illness or disability is an important part of maintaining a sense of self. According to Charmaz (1987):

> Being able to attain, maintain, or recreate a valued identity after an episode of chronic illness becomes crucially significant to these ill people who

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[2] According to Bury (1997), biographical disruption is the disturbing impact that the onset of chronic illness (or disability) has on self-perception and identity, "exposing the individual to threats of self-identity and potentially damaging loss of control" (p.124)

become acutely aware of the hardships in doing so. To fail to regain a valued identity to them is not just a failed attempt but is, moreover, a failure of *self* (p.286).

Charmaz' (1987) research brought to light two interconnected issues for studying identity: the role of preferred identities and the development of identity hierarchies. Charmaz (1987) defined "preferred identities" as symbolizing "assumptions, hopes, desires and plans for a future now unrealized…preferred identities represent identity goals" (p. 284). She continues:

> The concept of identity is more than stable or discontinuous identifications of actions, attributes and statuses through time…the concept of identity encompasses the person's vision of future selves, reflecting his or her hopes, aspirations, objectives and goals. In this sense, preferred identities serve as a source of motivation (Charmaz, 1987, p. 284)

Charmaz (1987) also points out that "the *timing* and *sequencing* of the person's illness figures in his or her definitions of a preferred identity" (p.291). This is one of the main reasons her theories have been so useful in relation to disability, as well as chronic illness.

Linked to the concept of preferred identities is that of identity hierarchies. According to Charmaz (1987), an "identity hierarchy becomes visible as ill people, over time, choose different types of preferred identities, reflecting relative difficulty in achieving specific aspirations and objectives" (p. 285). The identity levels described are: (1) the supernormal social identity; (2) the restored self; (3) contingent personal identity; and (4) the salvaged self (Charmaz, 1987). These identity levels are implicit or explicit objectives for personal and/or social identity that chronically ill people aim to realize (Charmaz, 1987).

The first identity level on the hierarchy is the supernormal social identity. In this identity level, chronically ill or disabled persons attempt to function at a more demanding level than their healthier counterparts, despite serious difficulties (Charmaz, 1987). It has been found that these ill people make every effort to maintain their "normal" identities so that an illness identity will not inundate who they believe themselves to be; in order to be taken as "normal", they think they have to be and do more than "just average" (Charmaz, 1987).

The second level on the hierarchy is the restored self. This identity level typically represents taken-for-granted assumptions that *recovery* should be the

sequel to illness (Charmaz, 1987). According to Charmaz (1987), although many ill persons simply wish to restore the threads of their former lives, three more specific types of restored self stand out: (1) the entrenched self; (2) the developing self; and (3) the assumed self.

The first type of restored self is the entrenched self. Restoring an entrenched self means being wedded to a self-conception situated in the past (Charmaz, 1987). A person restoring an entrenched self does not aim to move to new, different, or "better" identities (Charmaz, 1987). In contrast:

> individuals restore a *developing self* out of their sense of how they should shape their lives. Here, the direction of their lives concerns them as well as the *character* of the self they shape, rather than commitment to specific prior activities and prior identities (Charmaz, 1987, p. 303)

Those who aim for a developing self focus on the direction they wish to take toward potential selves (Charmaz, 1987). Thus, this type of restored self has much in common with Frank's (1995) description of those who tell quest stories.

The final type of restored self is the assumed self. This restored self is used by individuals whose "self-concepts are situated in assumptions about significant social relationships and social worlds with which they have long been associated" (Charmaz, 1987, p. 305).

The third identity level on the hierarchy is the contingent personal identity. This is an identity level which "an ill person, those involved, or both, define as *hypothetically possible*, but *questionable*, *risky*, and *decidedly conditional* due to possible further illness" (Charmaz, 1987, p. 307). The three conditions under which individuals pursue a contingent personal identity will be discussed in more detail in Chapter 4.

The salvaged self is the final identity level on the hierarchy proposed by Charmaz (1987). People who aim for this identity level do not wish to be identified by illness alone, and thus attempt to maintain some positive past self images.

While Charmaz's (1987) hierarchy is one of the most widely used in relation to identity during illness and disability, it is not the only identity reconstruction theory that has been proposed. Yoshida (1993) proposed a theory specifically for adults with traumatic spinal cord injury that was based around a pendulum, as opposed to a hierarchy. Yoshida (1993) explained:

The pendulum of self refers to a proposed life course of self and identity after the onset of traumatic spinal cord injury. This model suggests that the emerging self after spinal cord injury swings back and forth like a pendulum between the nondisabled and disabled aspects of self. Between these outer positions on the pendulum, individuals may pass through and experience different degrees of the nondisabled and disabled selves called predominant identity views. These predominant identity views reflect that self which is articulated implicitly or explicitly by the individual as the most important self to express over a period of time and/or within a particular situation (p.p. 222-223)

The five predominant identity views described by Yoshida (1993) were: (1) the former self; (2) the supernormal identity; (3) the disabled identity as total self; (4) the disabled identity as an aspect of the total self; and (5) the middle self. Movement along the pendulum was influenced by a number of experiences: (1) loss; (2) sustainment; (3) integration; (4) continuity; and (5) development.

The first predominant identity view posited by Yoshida (1993) is the former self. This identity view is based on who the person was prior to the injury; however, the total former self cannot be recaptured as the experience would likely transform the individual in a significant way (Yoshida, 1993). This identity view consists of 'core' and 'peripheral' aspects of the non-disabled self, where core aspects of self greatly define the individual. Depending on the age of the person when s/he is injured and their life experiences up to that point, an individual may posses more or less core aspects of self (Yoshida, 1993).

The second predominant identity view is the disabled identity as total self. In Yoshida's (1993) study, this was seen as a mainly negative identity. It is seen when an individual treats him/her self as disabled by expecting assistance from others without asking all of the time and/or believing that other people should know what a person with a SCI can and cannot do (Yoshida, 1993).

The third predominant identity view is the supernormal identity, and is very similar to Charmaz' (1987) identity level of the same name. This identity view is manifested when an individual engages in activities of an extraordinary nature requiring increased time and energy and/or the person refuses any assistance from others (Yoshida, 1993).

The fourth predominant identity view is the disabled identity as an aspect of the total self. This identity represents one aspect of the person, as opposed to encompassing or nearly encompassing the total self (Yoshida, 1993).

Figure 2. The Pendular Reconstruction of Self: Predominant Identity Views (Yoshida, 1993)

The former self

The supernormal identity

The middle self

The disabled identity as a part of the total self

The disabled identity as the total self
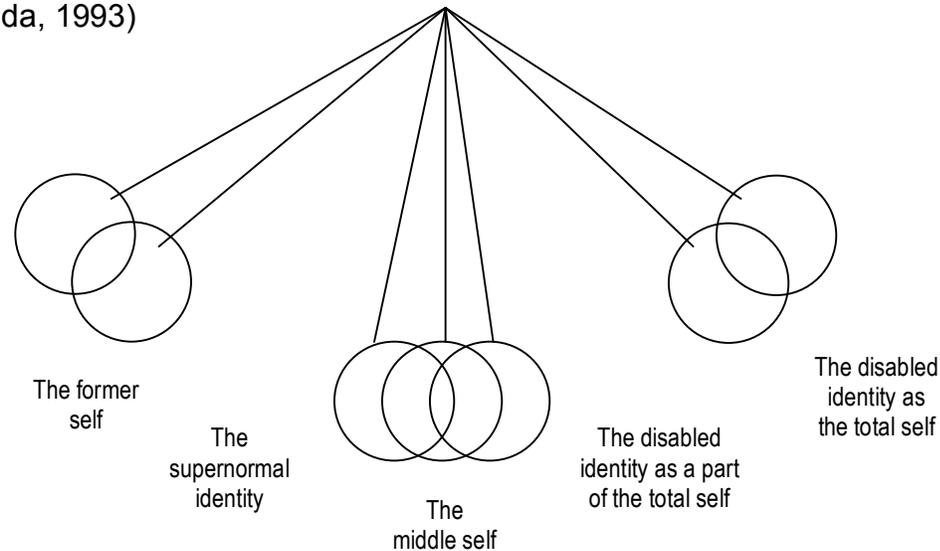
Finally, the fifth predominant identity view was that of the middle self. This self occurs when an individual moves closer to the middle of the pendulum, and refers to individuals who act upon both the non-disabled and disabled aspects of self (Yoshida, 1993).

The work done by Charmaz (1987) and Yoshida (1993) demonstrate what Smith & Sparkes (2006) comment on:

> researchers are united in their departure from the traditional Cartesian view that sees the self as a 'thing', existing apart from and having different substance than the body, and move toward theorizing selves and identities as active and interpretively constituted through embodied narratives (p. 170).

However, the body and the way it relates to self and identity are also affected by other topics, such as gender. Morris (1996) argued:

> there was a concern amongst disabled women that the way our experience was being politicised didn't leave much room for acknowledging our experience of our bodies; that too often there wasn't room for talking about the experience of impairment, that a lot of us feel pressurised into just focussing on disability, just focussing on social barriers (p. 13).

In the following section, I will cover the topic of gender more fully, and discuss the effect of gender on disability and the body.

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2.5 Gender

2.5.1 What is it?

Gender is generally an aspect of life that is taken for granted. Gender arrangements can be sources of pleasure but also sources of injustice and harm; thus gender is inherently political, and often the politics are complicated and difficult (Connell, 2002). Although some might think differently:

> being a man or a woman is not a fixed state. It is a becoming, a condition actively under construction…Part of the mystery of gender is how a pattern that on the surface appears so stark and rigid, on close examination turns out so fluid, complex and uncertain (Connell, 2002, p. 4)

Gender, above all, is a social structure (Petersen, 2006). It is not an expression of biology, nor a fixed dichotomy in human life or character; it is a pattern in our social arrangements and in the everyday activities or practices which those arrangements govern (Connell, 2002). Shilling (1993) explains that the body itself is not an empty shell which has gender placed into it; rather it forms a basis for, and actively contributes towards, social relations.

Because of this social aspect, language becomes an important aspect of gender, even though it does not provide a consistent theoretical framework for understanding it, as different languages make different distinctions (Connell, 2002). Connell (2002) goes on to explain:

> Many languages define a trichotomy of classes: masculine, feminine and neuter. Most contemporary discussions of gender in society, however, drop the third category and emphasize a dichotomy…In its most common usage, then, the term 'gender' means the cultural difference of women from men, based on the biological division between male and female (p. 8)

However, there are decisive objections to this definition of disability, and it is felt that they key is to move from a focus on difference to a focus on relations (Connell, 2002). It is felt that:

> gender is, above all, a matter of social relations with which individuals and groups act. Gender relations do include difference and dichotomy, but also include many other patterns… gender patterns may differ strikingly from one cultural context to another, but are still 'gender' (Connell, 2002, pp. 9-10)

Connell (2002) defined gender, using these social and cultural aspects, as "the structure of social relations that centres on the reproductive arena, and the set of

practices (governed by this structure) that bring reproductive distinctions between bodies into social processes" (p. 10).

Investigating gender alongside disability is important, because many feel that disabled women may suffer from "multiple oppression". This refers to the fact that the effects of being attributed several stigmatized identities are often multiplied (exacerbated) and they can be experienced simultaneously and singularly depending on the context (Vernon, 1999). Therefore, in the following section, I will discuss the effect that gender has on people with disabilities and how body, and embodiment, affect gender.

2.5.2 Gender, Disability, the Body, and Sport

Physical activity and sport is particularly relevant when discussing disability, the body and gender. In the previous sections, I have made some mentions of the effect sport has on disability and the body, and how society idealises physically fit bodies and sporting attainment. It is argued that the bodily practices found in mainstream sports exclude a majority of boys and girls from being able to participate in it freely without recrimination; as such, they shape children's future understanding of their own bodies in relation to gender, their role in sport and indirectly their own physical and social bodily identities (Paechter, 2003). In addition, whenever a comparison occurs between men's and women's sport – no matter what the sport – it seems almost impossible to explain the differences in ways which do not draw on and reproduce hegemonic discourses of gender difference (Wright & Clarke, 1999).

In light of generally lower participation rates in sport among women, and the different socio-cultural significance of sport and exercise for women, it is felt that women's stories of sport will differ markedly from men's (Carless & Douglas, 2007). It has been claimed that the influence of dominant images of gender cause many disabled women to "choose not to participate in sport because, in common with many able-bodied women, they are influenced more by commodified anti-athletic stereotypes of femininity" (Hargreaves, 2000, pp. 186-187). There is also a perceived fear of failure which can act as a strong deterrent for many people (and especially women) with disabilities to become involved in sport; and this is

especially true when you consider the fact that placing themselves in a sporting context is very likely to exacerbate the visibility of the very physical differences that lead to these feelings and perceptions in the first place (Brittain, 2004). However, it has been found that participant's stories of sport and exercise were:

> almost exclusively focussed on the *present* – the here and now – and on valued moments and good experiences within this present…a focus on the present, as opposed to the past or future, is significant in that it signifies a departure from the dominant restitution story of illness (Carless & Douglas, 2007, pp. 25-26).

Sexuality is also an important issue for women, especially if they are involved in sport or have a disability. Patriarchal society has kept close control over women's sexuality, what sexual activity is socially acceptable and to whom (Kallianes & Rubenfeld, 1997). In a society obsessed with 'perfection' and health, and intolerant of difference, non-disabled people view sexual activity by disabled people with discomfort or alarm (Waxman, 1993). Additionally, as Cox & Thompson (2000) discuss:

> The discourse of heterosexuality is particularly influential in the construction of sportswomen's bodies. For example, sporting discourse posits that the body must be physically powerful. However, heterosexual discourse, which depends on gendered distinctions for it's meaning, constructs the male body as strong and active and the female as weak and passive. The binary and contradictory logic of these two discourses is evident in the valorisation of male athletes for possessing strength and muscularity, and in questioning whether a sportswoman can, in fact, be a 'real' (read: heterosexual) woman…Female athletes, who deviate from the 'norms' of femininity by having short hair and athletic bodies, are challenged overtly or covertly about their sexuality (p. 8).

For those women who overcome the societal norms of 'femininity', a strong sporting identity can also prove somewhat of an "Achilles' heel"; indeed, from a psychological viewpoint, individuals with a strong athletic identity often exhibit greater signs of anxiety, depression and low self-esteem when their body project and athletic self-identity are disrupted by a traumatic event such as a career-threatening injury (Brewer, Van Raalte, & Linder, 1993).

The idolization of physically fit bodies and sporting attainment has led to a widespread social pursuit of the 'body beautiful'. It is believed that the ideal of bodily perfection "is central to the oppression of disabled people" (Huang & Brittain, 2006, p. 352). Mansfield (2008) feels:

a reality-congruent observation would be that men and women can experience, at the same time, liberating and repressive features associated with the pursuit of idealized bodies. The balance of liberating and repressive potential in pursuing an idealized body varies in relation to the long-term and complex links associated with fitness culture and gender, race/ethnicity, age, social class and disability (p. 100)

2.6 Rational and Purpose

In the previous sections, I have discussed at length the topics of disability, the body, narrative and gender, and covered much of the research that has been completed on them in the past and in more recent years. In addition, I have touched on the relationship between these topics and sport and physical activity. However, much work is still to be done, in each of the separate areas, and also in how all the different topics combine and interact.

Although disabled people have recognised that feminism can offer much to disability studies, the converse is not true (Sheldon, 1999). According to Lloyd (2001):

> The problems experienced by disabled women can be seen to be as much on account of their gender as their disability. Equally, however, disabled women have found themselves largely ignored by feminists and their perspective either lost by, or directly at variance with, much feminist analysis. Thus disabled women have been caught between, on the one hand, an analysis and movement in which they have been invisible as women, and one in which their disability has been ignored or subsumed, on the other (p. 716)

Smith & Sparkes (2005) have suggested, becoming disabled through sport is a major disruptive life event that instigates a multiplicity of difficult and complex issues that the person has to deal with. This is particularly so when negative life events disrupt the ability to engage in preferred activities, like sport, that have special importance to a person's identity and sense of self. Thus, traumas like becoming disabled are likely to be accentuated and take on a more imperious position in the lives of those individuals who shape their life significantly around the body's performance in sport. Although there have been some studies in recent years on becoming disabled through sport, these studies have focused exclusively on men (Smith & Sparkes, 2002, 2004; Smith & Sparkes, 2005b; Sparkes & Smith, 2002, 2003, 2005); thus nothing is known about women's experiences and the

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gendered dynamics involved when they become disabled through sport. Nevertheless, as Sparkes (1996) points out:

> a focus on epiphanous moments in the lives of elite sport persons who become ill, get injured, and/or acquire a physical disability can assist our understanding of the multiple body-self relationships that exist in contemporary society, and the manner in which these relationships get constructed and reconstructed over time (p. 465)

What, therefore, happens to women who have developed their bodies through sport, who have successfully negotiated a specific female identity and had it validated through a certain sport, but then experience a catastrophic athletic injury playing the very sport that has contributed so much to this process? How do they cope with crossing the border from the world of the able-bodied into the world of disability, where they remain to this day? How do they feel about their new and very different body? Just what types of life stories do women tell, how are they performed, and how does all this operate to shape both personal and public understandings of disability for women? Given that sport and physical activity has a range of sociological, psychological, and physiological health benefits, what promotes physical activity after becoming disabled through sport? Just what is involved in the process of narrative reconstruction of body-self relationships, and how does this process operate, for those participants who choose to becoming involved in disabled sport and those who choose not to do so? I hope, with this research, to be able to answer some of these questions by investigating women's experiences of becoming disabled through sport, exploring the stories they tell, their construction of self, and their bodily experiences over time.

CHAPTER 3: METHODOLOGY

3.1 Introduction

What is qualitative research? Qualitative research is difficult to define and to draw a precise boundary around its meaning. This is because it can mean different things to different people. That said, this does not imply that one has to either ignore or resolve definitional difficulties; instead, it creates an imperative in which the difficult, but not insurmountable task is to assume the responsibility to grapple with what is being said within the field of research and have a position regarding what qualitative can mean. This can be approached in two ways. One way is via common characteristics, and the other is via paradigmatic assumptions.

When looking at what qualitative research is, based on common characteristics, it should be noted that different characteristics will receive different emphases depending on the qualitative project (Creswell, 2007). For example, qualitative research is interested in *people.* It seeks to explore the *subjectivities*, *meaning* and *complexity* of an individual or group (Gubrium & Holstein, 1997). It is committed to *close scrutiny* and, instead of trying to identify cause-effect law relationships, focuses on the ways people *interpret and make sense of* their *experiences* and the *social world* in which they live (Gubrium & Holstein, 1997). It is *ideographic* rather than nomothetic (Sparkes, 1992). Researchers, moreover, do not seek to give 'the last final word' on a person, but offer an *unfinalized account* (Frank, 2005). Multiple forms of *representation* are available to them with which to communicate their findings (Sparkes, 2002). A researcher also uses *expressive language* and communicates in detail using *thick and rich description*. Moreover, instead of tightly prefigured, the design of a study is *emergent*. According to Denzin and Lincoln (2005):

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including fieldnotes, interviews, conversations, photographs, recordings and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (p.3)

Another way to begin to gain some theoretical purchase on what qualitative research can be, without aiming for a final answer, is to outline the paradigmatic assumptions that inform it. When looking at qualitative research via paradigmatic assumptions, we begin with a worldview, the possible use of a theoretical lens, and the study of research problems inquiring into the meaning individuals or groups ascribe to a social or human problem (Creswell, 2007). In the choice of qualitative research, inquirers make certain assumptions:

> These philosophical assumptions consist of a stance toward the nature of reality (ontology), how the researcher knows what she or he knows (epistemology), the role of values in research (axiology), the language of research (rhetoric), and the methods used in the process (methodology)(Creswell, 2003, p. 6)

In relation to ontology, when researchers conduct qualitative research, they embrace the idea of multiple realities; different researchers embrace different realities, as so also the individuals being studies and the readers of the qualitative study (Creswell, 2007).

Qualitative epistemology is subjectivist, and is related to how the researcher knows what she or he knows, and in a qualitative study this means that researchers try to get as close as possible to participants being studied, in order to 'know what they know' from firsthand information. Further, epistemologically speaking, the nature of knowledge is subjective and relative, in the sense that there can be no one "God's eye view" (Sparkes, 1992, p. 27) or all embracing 'Truth' concerning the social world. Thus, as Smith (1989) comments, "truth – or what we come to accept as true in terms of intentions, purposes, and meanings – is the result of socially conditioned agreement, arising from dialogue and reasoned discourse" (p.171).

For this study, I have adopted to use narrative research. Included in narrative research are biographical studies, autobiographies, life histories and oral histories (Creswell, 2007). In this specific type of qualitative design, "narrative is understood as a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected" (Czarniawska, 2004, p. 17).

But why should we conduct qualitative research? Qualitative research aims to capture qualities that are not quantifiable, such as feelings, thoughts,

experiences and so on (Gralton & Jones, 2004). The reason for turning to qualitative research is as follows: its inductive approach, its focus on specific situations or people, and its emphasis on words rather than numbers (Maxwell, 1996). Maxwell goes on to explain the five primary strengths of qualitative research. Firstly, it allows an understanding of the meaning. In a qualitative study, we are interested not only in the physical events and behaviour that is taking place, but also in how the participant makes sense of this and how their understandings influence their behaviour. Second, it allows an understanding of the particular context within which the participants act, and the influence that this context has on their actions; this is particularly important when studying a small number of individuals. Third, qualitative research allows the identification of unanticipated phenomena and influences, which allow the researcher to generate new, grounded theories. Fourth, it allows an understanding of the process by which events and actions take place. Finally, it enables development of causal explanations (Maxwell, 1996, pp. 17-20).

3.2 Methods of Data Collection
3.2.1 Sampling and Access

As much as one might want to, it is impossible to study everyone everywhere doing everything (Miles & Huberman, 1994). Patton (1990) states, "Qualitative inquiry typically focuses in depth on relatively small samples, even single cases (n=1), selected purposefully" (p.169). This is a strategy in which particular settings, persons, or events are selected deliberately in order to provide important information that cannot be obtained as well from other choices (Maxwell, 1996). In qualitative inquiry, sampling is driven by the desire to illuminate the questions under study and to increase the scope or range of data exposed – to uncover multiple realities (Crabtree & Miller, 1992).

As Sears (1992) states, "the power of qualitative data, however, lies not in the number of people interviewed but in the researcher's ability to know well a few people in their cultural contexts. The test of qualitative inquiry is not the unearthing of a seemingly endless multitude of unique individuals but illuminating the lives of a few well-chosen individuals. The ideographic often provides greater insight than

the nomothetic" (p.148). And as Wolcott (1995) puts it, "What can we learn from studying only one of anything? Why, all we can!" (p.171).

There are many different sampling strategies in qualitative inquiry. In regards to this study, I used one main type of sampling: purposive. This type of sampling involves subjects being selected because of some characteristic (Patton, 1990); however, purposive sampling comes in many forms. In this study, I used criterion based purposive sampling, which searches for cases or individuals who meet certain criteria. In the case of this study, I was looking for three main criterion: (1) the participants were women; (2) the participants were highly active prior to their accidents; and (3) the participants suffered a spinal cord injury while participating in a sport or physical activity.

Contact was made initially with the participants via the Back-Up Trust, which supports those affected by spinal cord injury. To ensure confidentiality, it was agreed that an open letter from ourselves explaining the project, along with a brief questionnaire seeking demographic details, would be distributed in one of the newsletters circulated by the network. The questionnaire ended by asking the respondent to indicate if they would agree to be interviewed, and if so, to provide their name and address in a stamped addressed envelope that was also supplied. Because the sensitive nature of the topics discussed could elicit strong emotions, the participants were supplied with a document containing a list of professional support and information networks that they could contact if they felt the need.

3.2.2 Interviews

For this study, I chose to use interviews as my main data-gathering technique because this method is able to focus onto areas of the participants' lives and experiences. It also allowed me the flexibility to follow through on areas of interest that the participants introduced. This flexibility was possible because interviewing is not merely the exchange of asking questions and getting answers; rather, it is a process involving two (or more) people, and their exchanges lead to the creation of a collaborative effort called the interview (Fontana & Frey, 2005).

There are many different types of interview, and a variety of terms to describe each one; however, in general, the three main types are: structured

interviews, semi-structured interviews and unstructured interviews. For this study, I chose to use semi-structured interviews for a number of reasons. The semi-structured interview has a more specific research agenda than the unstructured interview, but the informants in both types of interview describe the situation in their own words and in their own time (Holloway, 1997). In a semi-structured interview, an interview guide aides the researcher in focusing on the issues to be covered, while still giving informants the opportunity to report on their own thoughts and feelings (Holloway, 1997). Esterberg (2002) feels that semi-structured interviews are particularly useful for exploring a topic in detail or in constructing theory. The strength of this kind of interview is that the researcher adopts a flexible approach to data collection, and can alter the sequence of questions or probe for more information with subsidiary questions (Gralton & Jones, 2004), as opposed to a structured interview, which is formatted in a survey-style, and can often neglect the depth and complexity of the participants' experiences (Marvasti, 2004).

The purpose of my semi-structured interviews here was to learn about the life stories of the participants; therefore these can also be defined as life story interviews. According to Linde (1993):

> the notion of the life story means something like 'what events have made me what I am', or more precisely, 'what you must know about me to know me', where knowing a person specifies a range of linguistic and social activities and relations by the knowers (p. 20).

Corradi (1991) further explains:

> In sociology, the term 'life story' refers to the results of a research approach that consists of collecting an individual's oral account of his or her life or of special aspects of it; the narrative is initiated by a specific request from the researcher and the ensuing dialogue is directed by the latter towards his or her field of inquiry...life stories aim to explain and give meaning to social phenomena (p.106).

Linde (1993) points out that when listening to life stories, one must be aware that we change our stories at least slightly for each new listener. We change a story for a given listener as our relation to that person changes, as new events occur, as we acquire new values that change our understanding of past events, and as our point of view, our ideology, or our overall understanding changes.

3.2.3 Ethical Issues

There is no fixed or final definition of ethics in qualitative research, because unlike quantitative research which uses universal ethical guidelines, qualitative research uses non-foundational or relativist ethics. This does not mean that anything goes, but that ethics are always in progress. There are many guides as part of an on-going list that serve as a starting point for qualitative ethics, but these are not meant to serve as models. The importance of ethics is stressed by O'Reilly (2005):

> We are moving into people's daily lives, talking to them, watching them, asking them questions, thinking about what they are saying, writing about what they are saying, analysing what they are doing, and sometimes being critical about all these things. Some would consider this an inherently unethical activity. Luckily, rather than causing us to abandon research because of ethical problems, the result of the ongoing debates has generally led researchers into becoming more thoughtful, more informed, more reflexive, and more critical of their own actions, perspectives and responsibilities (p.59).

Following some of the ethical guides that have been suggested for qualitative research, informed consent was gained from the participants after full disclosure of the aims of the study, and their rights to withdraw from the study at any time was made clearly known to all participants. In addition, to strive to preserve the anonymity and confidentiality of the participants in this study, names and locations have been changed (Lewis, 2003).

3.3 Analyses

According to Schwandt (2001):

> broadly conceived, [analysis] is the activity of making sense of, interpreting, or theorising data. It is both art and science, and it is undertaken by means of a variety of procedures that facilitate working back and forth between data and ideas. Analysis begins with the process of organising, reducing, and describing the data and continues through the activity of drawing conclusions or interpretations from the data and warranting those interpretations. If data could speak for themselves, analysis would not be necessary (p. 6).

However, Smith and Sparkes (2005a) comment that:

> [t]here is no one form of, or 'best way' to conduct analysis. The approach chosen will depend on the purposes of the research and the questions being asked...in this light, advocating one kind of analysis over another seems less productive than asking how we might fruitfully combine different forms

of analysis, for certain purposes, in order to explore the *whats* and *hows* of storytelling, and generate different and more complex understandings of the world of sport and physical activity and everyday life...the two approaches complement each other and can be developed in tandem (p. 235)

Given that there are multiple ways of conducting an analysis, this study will be analysed using content and structural analysis (Lieblich, Tuval-Mashiach, & Zilber, 1998), both of which focus on *what* is being said, not *how* it is being said (Sparkes, 2005). These two types of analysis were chosen in order to gain a deeper understanding of the participants' experiences, and were based on the strengths of these strategies.

According to Smith and Sparkes (2005b), when using content analysis, the researcher seeks central themes, typologies, or instances of paradigmatic categories within the narratives told and looks at the content or defined categories of the story as manifested in separate sections of the narratives told. As a part of this process, themes are allowed to emerge and concepts are developed from stories in an inductive manner (Smith & Sparkes, 2005b). Here,

the original story is dissected, and sections or single words belonging to a defined category are collected from the entire story or from several texts belonging to a number of narrators (Lieblich et al., 1998, p. 12)

Content analysis was chosen because it is valuable for developing general knowledge about the core themes that make up the content of the stories generated (Sparkes, 1999). It also has the potential to vividly reveal the lived experiences via the storied themes presented (Smith & Sparkes, 2005a).

Structural analysis was also used because it considers the form, kind, purpose and conventions that structure the telling of the story (Sparkes, 1999). Structural analysis "focuses on the formal plot and organisation of the narrative to tease out the distinct structures that hold it together with a view to identifying it as a particular narrative type" (Smith & Sparkes, 2005b, p. 1096). According to Lieblich et al. (1998), "analysing the structure of a story will therefore reveal the individual's personal construction of his or her evolving experience" (p.88). This type of narrative analysis is useful because it provides important insights into the ways stories told by specific groups are patterned, and the manner in which key elements, such as threats to self-esteem and identity, connect with this pattern

(Sparkes, 1999). Additionally, as Gergen (1999) has suggested, the choice of narrative a person adopts, but may not be fully aware of, can have a strong influence on what kind of story he or she is likely to tell. Smith and Sparkes (2005a) further explain:

> In this sense, analyses of structure and form, and identifying what type of plot-line people may embody, offers the opportunity to illuminate the ways personal stories are connected to and shaped by wider public and metanarratives. In doing so, there is the possibility of, for instance, first recognizing entrenched cultural narratives and dominant 'master' narratives and then understanding how they constrain and/or empower people (p.233).

3.4 Representation

In recent years, qualitative studies have begun to show a more widely ranging array of tales. Tierney (1999) makes the comment:

> What one assumed was the correct way to present data is no longer accepted without question; even the idea of *data* raises postmodernist eyebrows where one questions the meaning of what makes a fact a fact, what makes a text a text (p.307)

While scientific and realist tales are still the most commonly used ways to represent quantitative and qualitative studies, respectively, there is now a lot of variety in the way studies are being represented. Confessional tales, autoethnography, poetic representations, ethnodrama and fictional representations are now becoming much more widely accepted in the academic community; nevertheless, I have decided to write this study in the form of a realist tale, because as Fine (1999) states, "there can be little doubt, even among the critics of the realist approach, that some of the classic naturalistic ethnographies have produced startling, compelling, and practical results that have demonstrated their worth" (p.538). Therefore, realist tales do have a contribution to make (Sparkes, 2002).

A realist tale is, essentially, a qualitative tale reported in a quantitative manner. Realist tales are defined by three main characteristics: (1) experiential authority; (2) the participant's point of view; and (3) interpretive omnipotence.

The first main characteristic of realist tales is experiential authority. In this type of tale, the most striking characteristic is the almost complete absence of the author from most segments of the finished text (Van Maanen, 1988). The author uses the passive voice in order to construct authority and objectivity "so as to

obscure and apparently distance the disembodied author from the data" (Sparkes, 2002, p. 44).

The second main characteristic of realist tales is the participant's point of view. Realist tales are characterised by extensive, closely edited quotations (Van Maanen, 1988). These are used to convey to the reader that the views expressed are not those of the researcher but are rather the authentic and representative remarks transcribed straight from the mouths of the participants, thus foregrounding the participants' voices, and allowing the reader to gain important insights into the participants' perceptions of the injury experience (Sparkes, 2002).

Finally, interpretive omnipotence is the third main characteristic of realist tales. This relates to how "the interpretations of the author are made compelling by the use of a string of abstract definitions, axioms, and theorems that work logically to provide explanation. Each element of the theory is carefully illustrated by empirical data." (Van Maanen, 1988, pp. 51-53). According to Sparkes (2002), "when well-constructed, data-rich realist tales can provide compelling, detailed and complex depictions of a social world" (p.55). Although often subjected to criticism, realist tales are surely useful, as they permit us to build knowledge, comfortable in the belief that we are learning about the contours of the world (Fine, 1999).

3.5 Criteria

According to Schwandt (1996), criteria for qualitative inquiry are "standards, benchmarks, and in some cases, regulative ideals, that guide judgements about the goodness or 'quality' of inquiry processes and findings" (p.22). In the past, the work of Lincoln and Guba (1985) was frequently used to set criterion with which to judge work in what they called the 'naturalistic' paradigm. As criteriologists, they believed that these criteria for judging qualitative work could be permanent and universal (Sparkes & Smith, 2009). As Sparkes and Smith point (2009) out,

> the inherent danger of such a criteriological approach is that specific predetermined criteria are wittingly or unwittingly called upon in an exclusionary manner to produce a closed system of judgement that can only operate within a very narrow range of what constituted legitimate research (p.494)

In addition, there were a number of specific problems revolving around these criteria, which Guba and Lincoln (1989) later recognized:

> Relying solely on criteria that speak to methods, as do the parallel criteria, leaves an inquiry vulnerable to questions regarding whether stakeholder rights were in fact honoured. To put the point more bluntly, prolonged engagement and persistent observations (or any other methods one might choose) do not ensure that stakeholder constructions have been collected and faithfully represented. So reliance on pure or pristine method alone is insufficient to guarantee that the intent of the inquiry has been achieved (p.245)

With regard to judging qualitative research, this study follows the work of Smith (1993), Sparkes (1998b) and Sparkes and Smith (2009) by taking the view that criteria are usefully thought of as a list of characterizing traits that have been developed as a 'starting point' for qualitative inquiry, rather than an absolute or preordained standard against which to make judgement. In other words, it is a description of what one *might* do, but is not a mandate of what one *must* do across all contexts and on all occasions (Sparkes & Smith, 2009). Because of this list-like quality, however, Smith and Deemer (2000) offer the following warning:

> The use of the term *list* should not be taken to mean that we are referring to something like an enclosed and precisely specified or specifiable shopping or laundry list. Put differently, to talk of a list in this sense is not at all to talk about, for example, and accumulation of 20 items, scaled 1 to 5, where everyone's presentation proposal is then numerically scored with a cut-off point for acceptance. Obviously, to think of a list in these terms is to miss the entire point (p.888)

Sparkes (2002) argued that the difference between alternative forms of inquiry, "in terms of their process and products, need to be acknowledged so that each can be judged using criteria that are consistent with their own internal meaning structures and purposes" (p.199). Therefore, from lists made by a number of authors, I have chosen some criteria that I feel are appropriate for judging this research.

Firstly, *substantive contribution* looks at whether a piece contributes to the understanding of social life (Richardson, 2000). Secondly, *impact* questions whether the paper affects the reader and whether or not it generates new questions (Richardson, 2000). Thirdly, *reflexivity* examines whether the author is cognizant of the epistemology of postmodernism, as well as issues to do with data gathering, ethical issues and self-awareness (Richardson, 2000). Fourthly,

coherence looks at the way different parts of the interpretation create a complete and meaningful picture (Lieblich et al., 1998). Finally, *width* examines the comprehensiveness of the evidence (Lieblich et al., 1998).

3.6 Summary

Overall, this study uses qualitative research, following a social constructivist paradigm, on four women who have suffered spinal cord injuries. Data was collected through semi-structured interviews. Ethical guidelines such as informed consent, ability to withdraw, and confidentiality were all discussed with the participant and permission was granted for the research. The data obtained in this study has been analysed using content and structural analysis, because of the strengths these analyses. The thesis will be presented in the form of a realist tale; however, criteria based on the 'letting go' perspective have been suggested as suitable judgement criteria for the study.

CHAPTER FOUR: RESULTS

4.1 Introduction to the Participants

This study involves four active women who became disabled while participating in sports or physical activities. In this chapter I will give a short introduction for each woman, in order to give the reader a bit of insight into their life and history.

Amanda (all participants a have been assigned pseudonyms), now 47 years of age, lives in a rural community with her son, Michael. Growing up, she was the eldest of four children and was the first in her family to learn to drive and to get a passport. After A-levels, she worked as a microbiologist before studying to become a nurse. She was always active and loved to dance, and did her first parachute jump as a fundraiser for a local hospital. She immediately loved skydiving and soon dedicated the majority of her free time (and money) to the sport. In 1995, at the age of 32, her parachute tangled on opening in a training dive. Following procedure, she released the tangled chute and attempted to release her second parachute. Unfortunately, due to a defect in the harness she was using, the first parachute did not fully release and the reserve tangled up in the dangling main chute. This resulted in her falling 13,500 feet at full speed. Her injuries were significant, and she was not originally expected to survive; however, among her many injuries, she damaged her spinal cord at the level of C 5/6.

Rachel, now 35, lives in a large town near her sister, Claire. While both she and her sister attended school in the United Kingdom, for much of her childhood her parents lived in the Middle East. This led to spending school holidays with her parents overseas. During her school years she kept active with school sports and horse riding. In 1994, at the age of 20, she was on holiday visiting with her parents when she dove into shallow water and damaged her spinal cord at the level of C4, C5 and C6.

Michelle, now 48 years old, lives with her mother at their house in a rural community. She rode horses from a very young age, and was involved in show jumping and teaching. After finishing school she found work as a secretary for a catalogue company, which left her weekends free to work with the horses. In 1984,

at the age of 23, she was clipping a horse when it was frightened by a bird and knocked her back. When she fell she hit her head on a brick wall. She was still able to move her arms and legs so, unaware that she may have a spinal injury, the paramedics moved her to the ambulance without a backboard or neck brace. It is unclear whether her injury was made worse by this treatment. The doctors were suddenly made aware of the seriousness of her injuries when she stopped breathing after she arrived at the hospital. Like Amanda, her injury occurred at the C5 / C6 level in her spine.

Karen, now 42, lives with her husband and son at their stud farm in a rural community. She was interested in horses from a young age, and owned her first horse at age 11. She left school at 15 after finishing all of her exams and immediately started working on a horse farm as a live-in stable hand. She worked at this job for eight or nine weeks, and had just turned 16 when she had her accident. She was riding a young horse that she later found out had not been broken. After trotting over a placing pole, the horse began bucking and threw her off. She was immediately aware of a loss of sensation, as her spinal cord was damaged at the C6 / C7 level.

With these brief biographical descriptions in mind, I will now discuss the findings of this study in relation to: (1) the body; (2) narrative; (3) identity; (4) dependence; and (5) relationships.

4.2 Body

One of the main issues that can come into play when conducting research on the body is that, in everyday life, we pay little attention to our bodies. Leder's (1990) description of 'dys-appearance' illustrates the significance of the social atmosphere on the body-self, stating that in everyday life our experience is characterised by the disappearance of our body from awareness, saying the "body not only projects outward in experience but falls back into unexperienceable depths" (Leder, 1990, p. 53). However, this customary mode tends to be profoundly disrupted in the context of factors such as pain and disease (Bendelow & Williams, 1995). Here, the body becomes unceasingly present in experience, albeit in an alien and dysfunctional manner; thus "the body appears as a thematic

focus of attention, but precisely in a dys-state" (Leder, 1990, p. 84). Nevertheless, this dys-appearance of the body also allows researchers to more deeply understand the experience of impairment, because people can reflect on their bodies rather than taking them for granted.

Previous research, using this dys-appearance of the body to study the effect of disability on men's embodied masculinity, found that men suffered a loss of their masculinity following a traumatic SCI (Sparkes & Smith, 2002). This is because the body is often the "central foundation of how men define themselves and how they are defined by others" (Gerschick & Miller, 1995, p. 183). In this study, I was interested in how active women viewed their body following a traumatic SCI, and whether they would feel a loss of their femininity similar to the men's loss of masculinity. I was also interested in whether the body is also the "central foundation" of how women define themselves. One way to examine the embodied self is to explore how women's experience of their bodies compared to Frank's (1995) description of ideal bodies.

4.2.1 Ideal Bodies

As explained in chapter two, Frank (1995) described four ideal body types, which are created as the body faces four problems of embodiment and defines itself within four continua of responses. While real people are not ideal bodies, they will often represent distinctive mixtures of ideal types (Frank, 1995). Figure 1. (p. 26) is a representation of the four body problems, the continua of responses, and the ideal bodies thus created.

Of the four ideal body types described by Frank (1995), the two that were most frequently in evidence in the stories told within the interview setting were the communicative and the mirroring bodies. According to Frank (1995):

> the communicative body-self is not only an ideal type, but also an *idealized* type. Its specifications are not only descriptive but provide an ethical ideal for bodies. Again, no actual body fits this ideal for long, though many bodies may approximate it in different ways (p.48).

He goes on to explain further that

> the communicative body accepts its *contingency* as part of the fundamental contingency of life…bodily predictability, if not the exception, should be

regarded as exceptional; contingency ought to be accepted as normative (Frank, 1995, p. 49).

In this study, three of the women especially seemed to exhibit this aspect of the communicative body: Michelle, Rachel and Karen. While none of them ever specifically mentioned bodily predictability or contingency, all of them appeared to take their disability in stride and move on with their lives. For example, Michelle commented:

> It's just one of those things, like the accident, you can't do anything about it…well then you just have to get on with it, haven't you?

Similarly, Karen commented:

> It's still never going to stop happening to people, and how people deal with it and their families deal with it around them…You know, it happens, and it can happen and life doesn't need to stop. It doesn't need to stop. It is what you make it, and that's it.

Finally, Rachel explained:

> I was awake throughout the whole thing…I *knew*, you know. And I knew it wasn't going to get any better, do you know what I mean?...I can honestly say that I was never depressed about [the SCI]. It's just sort of, that's it, you know? That's what's happened so we had to deal with it…it's just something that you just dealt with.

These comments signal how these women accepted bodily contingency as a part of life, and viewed it as normative. In addition to this acceptance of contingency, the communicative body is associated with itself; this association and contingency are contextualised by the qualities of *being dyadic* and *producing desire*. The communicative body, like the disciplined, mirroring and dominating bodies, is not simply biological; it is also a story. The communicative body *communes* its story with others; the story told through communicative bodies invites others to recognise themselves in it (Frank, 1995). Indeed, these women explained the importance speaking to other people and sharing their stories. Michelle remarked:

> I've always been chatty, and then when I had my accident, I didn't speak, and one of my friends in the village said "Michelle, you've lost the use of your legs, you didn't lose the use of your voice...you can either speak to people or you don't". You didn't realise that you're not speaking…and then you realise soon, if you don't ask for help, people are frightened to ask, frightened that they'll upset you…or maybe you could be a bit rude to them back.

Karen also mentioned the importance of talking to others:

> I think the biggest thing with people is talking to them; explain, let them see…you know, I've always been that type of person I suppose. It's like, all my staff, the girls who have worked for me…because we're only a small business, you get very fond of a lot of them. But even in their interview when I don't know them, it's like…always talk to me, whether you have a problem with work, home life, finances, what have you. I can't help you if I don't know about it.

Even Amanda, who shows little other evidence of having a communicative body, stresses the value of talking to others:

> At first at Michael's school, people sort of didn't speak to me. They were avoiding me because they didn't know what to say to me. So the kids sort of avoided me too, and then eventually the kids just got used to me being "Michael's mum" and…they got used to me being in a wheelchair…it's the parents that feel awkward and not the kids actually. I think people will deal with you with a bit of "Uh, I'm scared!"; but they're not actually scared of you, they're scared of how they will deal with you, cause of their inexperience….If you're just completely natural and open with them, I think it puts people at ease a bit. But people I think are generally scared when they see you because they don't know how to react.

The second ideal body exhibited by the women in this study was the mirroring body. Frank (1995) explains

> the mirroring body defines itself in acts of *consumption*. The body is both the instrument and object of consuming: the body is used to consume, and consumption enhances the body: feeding it, clothing it, grooming it…this body-self is called mirroring because consumption attempts to recreate the body in the image of other bodies: more stylish and healthier bodies (p.43).

He stresses that the primary sense of this reconstruction is visual – the body seeks to become an image of the image it idealizes (Frank, 1995). While the mirroring body is similar to the communicative body in that it is associated with itself and it produces desires, these desires are monadic, unlike the communicative body's dyadic desires. In addition, for the mirroring body-self, the body is now a surface, with the visual being the primary (Frank, 1995).

Whereas only three of the women in this study displayed salient features of the communicative body, all four of the women in this study displayed aspects of the mirroring body-self. Of the body problems that create these ideal body types, the one most commonly cited by these women was that of predictability. However, unlike the predictability of performance sought by the disciplined body, these

women yearned for predictability of appearance; the mirroring body fears disfigurement. For example, Rachel commented:

> I just want to keep looking nice if I can…at the end of the day I am a woman and I want to look like a woman and dress nicely and things…I still would never dream of leaving the house without makeup on or anything like that…people won't approach you if you don't look nice…and if you don't care about yourself, then people are going to think "well why bother"…Clothes and everything…I'm very paranoid about short trousers, cause I'm sitting all the time, and it's just like you thought, "what if my [urinary] leg bag hangs down and people will see my [urinary] leg bag…sometimes you had to be a bit blasé about it, but I just think, "no!"…just the small things…it's very shallow really.

Rachel's worries about her urinary leg bag showing are a clear example of the disfigurement the mirroring body fears. Her clothes and appearance mean a great deal to her, because she feels that not meeting certain expectations will make her unapproachable. Karen also suggested a mirroring body during the interviews, and reinforced how the body is both a social construction and a biological reality (e.g. pressure sores):

> I am a huge jeans fan. I don't go out if I can't wear my jeans. You know, I'm not allowed to wear jeans when you have a spinal injury cause of all the seams and they'll give you pressure sores – crap! Absolute crap. I daresay if you bought the wrong type or fit, skinny ones that cut you up the ass then yes they would. But of course, I need a 36" leg to look good, I'm six foot nearly…I can't wear dropped waists, I hate bootlegs…all I want to do is buy a pair of jeans and I can't…I never feel I look nice at times. You know, when you want to dress up. I will dress up all winter; I love dressing up during the winter…I don't like dressing up during the summer…that's when you think, "this is due to the chair and the accident". But that's the only time I ever get down, is when I want to try and dress up and look nice.

Moreover, Michelle illustrates how the mirroring body focuses on the visual, external body:

> I don't like skirts and dresses now, cause they're too much distress. I mean, when you're going along and your skirt blows up…I wore trousers before so I wear them now…You always like to be nice when you go out, your hair done and your makeup on and nice clothes…I think there's a time and a place [for dressing up]…I've never been a girly-girl…someone's birthday, and you all find something nice to wear and you get your hair done and your makeup on, but I don't do it every morning! I didn't before [the accident]…makeup and horses don't go together.

Finally, while Amanda commented on her frustrations with clothing, she seemed less affected by her external appearance than the other participants.

Nevertheless, she was also aware of how appearances could affect how others viewed her:

> I can't wear what I'd like, I have to wear what's comfortable…if I look at a pair of trousers now, I look at the seams and look for, are there rough seams because they're going to cause pressure sores. So I can't wear what I used to wear, and I don't have the same choice…I hate wearing clothes, cause they're just so cumbersome. In the summer, I'll go out in just shorts and a crop top…And my physio went out with me one day and he didn't even notice what I was wearing until we were in the middle of the street and he noticed everybody on the bus was staring at me…I was so prejudiced without knowing before my accident. I remember seeing somebody in a wheelchair before my accident and she was dressed, but her clothes were all ruffled up and her hair wasn't combed properly at the back and I remember thinking "oh she's let herself go". She hasn't let herself go, she's got "Home-don't-care" not brushing her hair and not putting her clothes straight and I was completely unaware of that.

These comments clearly show that all of the women in this study, at some point, displayed the body-self of the mirroring body. They also signal that the women's psycho-emotional well-being was all affected by the mirroring body's fear of disfigurement, and how that disfigurement would be viewed by the general population. Indeed, as we can see by Karen's comment that she "gets down" when she wants to look nice, the visual surface of the body can have a lot to do with how these women feel about themselves. This preoccupation with body image was another main issue that emerged from these women's stories.

4.2.2 Body Image and the 'Body Beautiful'

Body image relates to a person's perceptions, feelings and thoughts about his or her body, and is usually conceptualised as incorporating body size estimation, evaluation of body attractiveness and emotions associated with body shape and size (Grogan, 1999, 2006; Muth & Cash, 1997). It has been found that unwanted physical changes to our bodies due to illness, accident and ageing can affect our body image, resulting in reduced quality of life and self-esteem (Anderson, 2000; Gannon, 2000; Rumsey & Harcourt, 2004; Thomas-McClean, 2000). Paquette and Raine (2004) found that women's narratives revealed that body image is not a static construct, but has multiple elements, and is dynamic and fluctuating.

Authors have argued that our society values bodily characteristics that people with physical disabilities are less likely to possess, including physical fitness, sporting attainment and the 'body beautiful' as it is represented in the media (Lawrence, 1991; McCabe & Ricciardelli, 2001). Many women not only face challenges using their bodies to their full potential but are also challenged to create socially perfect bodies because of images of grace, beauty and femininity (Cronan & Scott, 2008). The media portray the external body as something that can be perfected by one's choices in behaviour (Chau et al., 2008). Feminist writers have argued that disabled women are particularly vulnerable to the psychological and emotional damage that can result from discursive representations of the idealised female body – a consequence of the intermeshing of disability and gender discourses (Meekosha, 1998; Thomas, 2007; Wendell, 1996; Wilde, 2004). Indeed, body image was an important aspect that came into play in these women's stories.

The images of the "body beautiful" and the expectations that the external body can be perfected affected the women in this study greatly, even when they felt it did not. For example, Michelle stated:

> [I've] never been like, a magazine-y person that wants to be like that, no.

Yet she also commented on a number of issues related to the "body beautiful", and was especially concerned about her weight:

> I think whether you put weight on, or don't – cause that's the easiest thing from sitting down, you do put weight on…I think the worst thing is you put weight on…around your stomach, you've got no stomach muscles, you can't even pull it in, and you're trying hard anyways…your legs are there, you don't want them to be horrible do you?

Thus, even though Michelle felt that the images in magazines of the body beautiful was never something she strived to attain, the possibility of weight gain in the chair, and the way her stomach looks is something that played on her mind. While Karen failed to mention any specific media sources, she did comment on the frustration of trying to buy clothes and look nice:

> What can I wear? You know, I have to be so careful, cause you can't wear a low waist thing…you always have to watch because you always end up with a bit of a belly, whether that's just natural, everyone with a wheelchair seems to have a bit of a belly. But is that because I've had a child or what? No stomach muscles…It does affect how you feel about yourself…Which is why I prefer dressing up in the winter…everyone else has got their skimpy

summer dresses on…I just don't look nice in summer clothes. I don't feel good in summer clothes.

For Rachel, whilst she displayed agency and never simply locked into media portrayals of the ideal female body, her body image appeared to be subtly affected by celebrities and images in the media, as well as her friends:

> I just think you know, Victoria Beckham and the size they get to, its just like, is that a real goal? And then it is inevitably like, constantly on a diet, but it doesn't happen. I'm often baffled…what do they eat in a day, or do they actually eat? It's a constant enough thing that I think it's a very high standard to keep up to if you're going to buy into it…I was one of those that lived on a diet, I'm much more paranoid now about my weight and everything…I just know if I don't really watch what I'm doing I will just get big quickly…I know I've always been a big girl, broad and tall, and my friends are always skinny, so I've always struggled to be…I've always been in a constant battle with weight I'd say. It's just a high standard to try and…to try and not put yourself to that standard, although it's difficult not to.

In addition, Rachel seemed greatly affected by her perceptions of her sister:

> I still want to make sure I look ok…Claire doesn't bother, she's lucky she's naturally attractive, so she doesn't need to put the work in…she can just stick her hair back and look good, you know? But it's something I've always had to work at.

Finally, Amanda seemed to be aware of the effect the media had on others, but claimed that age had helped her resist simplistic portrayals of the female body and "get past it":

> There's the usual hype about "you must be super-slim"…that's such a big industry and it makes so much money I don't think we'll ever combat it. Cause it's nothing to do with health or anything really, it's to do with big corporations making money…so there is a lot of pressure, but I think I've got past it. And it's age, I don't think it's anything to do with [the disability] experience, it's just as you get older you are swayed less by it

However, age in itself seems to have brought about some changes in Amanda's body image:

> I'm menopausal, so I've found that…I haven't actually put on weight, but everything's just got looser…Whereas I just wore what was comfortable before, now I feel that it's essential to wear a bra because [I'm] just so saggy…so there's body changes like that which is quite saddening. But that's the same as if I was walking around.

Overall, all the women in the study do seem to be affected by body image issues; for example, worry over weight gain and matters of self-esteem. However, their body image concerns are all affected in varying degrees by the media,

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friends/family and age. In addition, while they all appear to be aware of body image issues, each seems to be at a varied level of acceptance and comfort with their body.

4.2.3 Developing Comfort with the Changed Body

Chau et al. (2008) conducted a study on women living with spinal cord injury and found that there was a fluid, three-stage process by which women became comfortable with their changed bodies (see Figure 3). This process is felt to span from early rehabilitation to community reintegration (Chau et al., 2008). "Discomfort" in the analysis referred to a sense of uneasiness related to one's own body, while during the second phase, "moving towards comfort", individuals employed strategies progressing from social isolation to representing themselves in a positive light through appearance and behaviour. The final phase, "comfort", is fulfilled by educating others about visible disabilities and by surrounding oneself with an accepting environment (Chau et al., 2008).

The women in this current study were found to be at various phases in this process. The first phase of developing comfort with the changed body is discomfort – this often occurs during the early phases of rehabilitation when individuals are just beginning to familiarise themselves with their new bodies (Chau et al., 2008). Amanda showed us her discomfort with her changed physical body immediately following the accident when she commented:

> I was really shocked at my body image when I had the accident…I didn't have a lot of mirrors and like, I've got a mirror there now, and I have that so I can see that I'm sitting straight in the wheelchair, but I actually don't look in a mirror half as much as I used to. Probably, if I'm honest, I avoid looking in a mirror, because that's not how I feel.

Another source of discomfort according to Chau et al. (2008) stems from the loss of control experienced when in a rehabilitation facility, and usually related to the areas of privacy and treatment approaches. Karen felt this discomfort acutely in her rehabilitation experience:

> Never really getting to grips with the physio, that was the one thing. You know, "you should be able to do, you should be able to do…". The transfers, if I ever managed to do it I seemed to pinch my skin and end up having a week in bed than cause I got a pressure sore. That was what got me down more than anything, was "you should be able to do, you've got to

build your strength"…Do you know how hard I'm trying?…I felt I was put in a box, that I should be able to this, I should be able to do that, I should be able to do something else. My lesion is C6/C7, which is like, if you're C6 you're one, if you're C7 you can do this and you can do that. And I've got bits I can do which I shouldn't be able to and bits I can't do which I should be able to…just because you're a level doesn't mean that you can do this, and if you're that level you can do that. But they viewed it as that…And I was expected to do it

Figure 3. Developing Comfort with the Changed Body (Chau et al., 2008)

COMFORT
⇒ Educating others
⇒ Immersion within an accepting environment
• People
• Activities

MOVING TOWARD COMFORT
⇒ Social Isolation
⇒ Positive self-representation
• Appearance
• Behaviour

DISCOMFORT
⇒ The changed physical body
⇒ The loss of control
• Lack of privacy
• Lack of individualised treatment
⇒ Altered social interactions
• Unprepared for community
• Stares
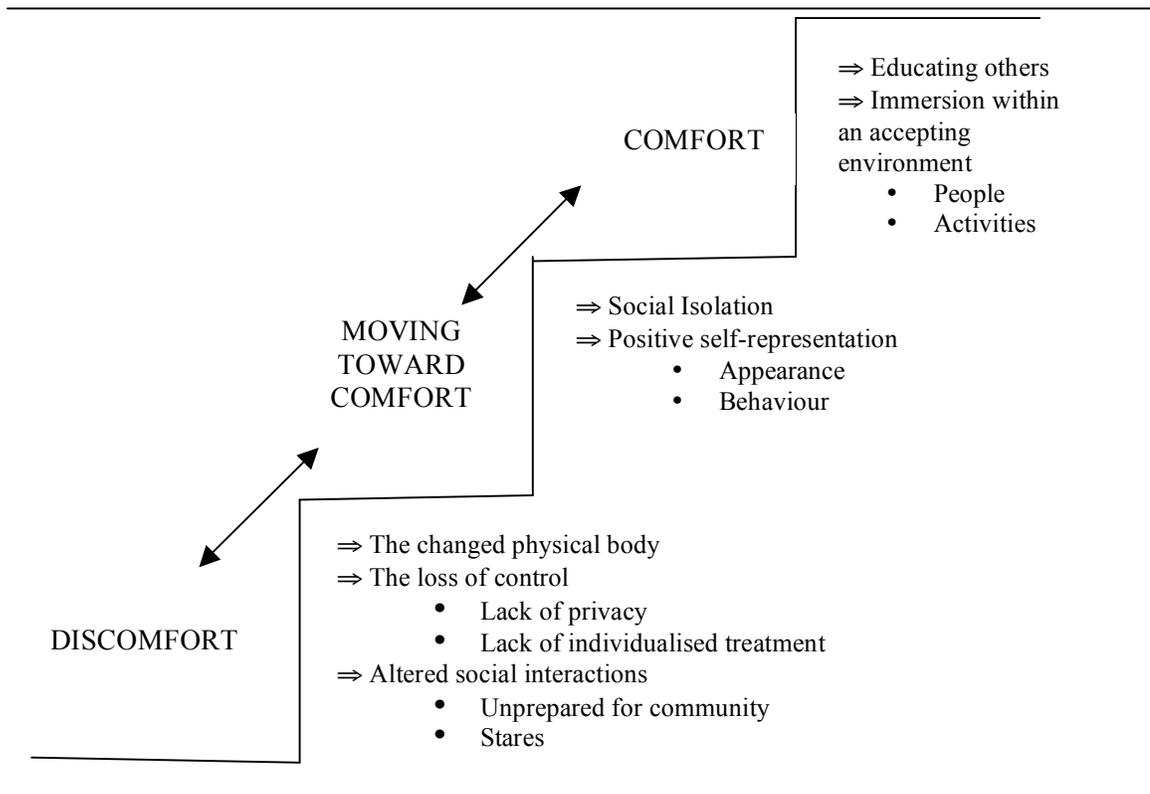
Rachel also felt discomfort due to feelings of a loss of control immediately following her accident, indicating that her acceptance of the contingency of the body (noted earlier) took some time to develop. However, in her case it does not appear that this discomfort was tied directly to the rehabilitation experience. Instead it seems to be related to self-confidence:

I'm very nervous in my chair…it's just like, very worried about falling out of my chair…getting onto the balancing bed, or whatever it's called, you know, practicing my balancing and everything, I just couldn't do it…I was just in tears and wanted to get off

Amanda, like Karen, felt discomfort due to her rehabilitation experience. Specifically, she felt her physiotherapy was like a factory line:

Rehab shouldn't be called rehab. It felt like able-bodied individuals go into this big factory as individual people, and at the other end of the factory on a conveyor belt came disabled people sat in a wheelchair. And they're all on the same drugs, have the same life and the same carers, and absolutely everything prescribed by somebody else. And this somebody has trained them and taken away any spirit and hope they've got…I felt like a piece of meat on a conveyor belt…that was the torture…being paralysed was the easy bit, it was coping with everything else!

In addition to her rehabilitation, Amanda felt dehumanising feelings associated with the care addressing bodily functions (Chau et al., 2008), and especially feminine issues:

Women's stuff, I thought that there'd be a way of dealing with it if you're in a wheelchair, and somebody would enlighten me and tell me how to deal with it. But no, there was nothing…in the early days, the first nine months I came home…I didn't have a bath for nine months because my bathroom wasn't converted…so for nine months I had bed baths. And so my day when I was on a period would be: two women would come in and bed bath me, give me a quick wash down below and then they'd stick a sanitary towel in my knickers which they would then sit me on all day without changing because I'd chosen not to go the tie-two-tampons-together route…and in the evening, they would hoist me out of the chair…my clothing and everything would be stained, they would take them all off, give me a quick wash, stick another in place and that's how it would be dealt with. And my clothes would be put in a bucket somewhere for somebody else to deal with.

Finally, individuals would feel discomfort due to altered social interactions, including feeling ill-prepared for living in the community (Chau et al., 2008). Karen described this discomfort when she said:

I didn't realise the impact of spinal [injury]…I don't think I even knew about it as such to be honest. I'd never heard of it, you know, never cropped up in our lives. So I suppose I was frightened, because I didn't know, that was the biggest thing. If I was older I probably would have known more, I would have realised the impact on my life it was going to have…I don't ever remember talking to any counsellors about it. I don't ever remember anybody saying to me, "you will never walk again"…I don't ever remember anybody coming and saying " it will affect this in your life, it will affect that in your life, you will never be able to do that…" you know?...The most scary time was coming home, everything's safe in hospital

Another source of discomfort is how the changes to the physical body created a dependence on others. Opinions of this dependence varied widely in the women of this study, but all of them admitted to a greater need to be dependent on other people. For example, Michelle commented:

You've got to be dependent on someone...like I can get in the car and drive, but I need someone to give me a hand in, and I can't put my chair in and get in the car on my own, so I do need help.

In the study conducted by Chau et al. (2008), they found a significant source of discomfort stemmed from being stared at by others. However, in this study, none of the women expressed this issue. In fact, Rachel commented:

I've just had a really good experience being in a wheelchair...I don't think people are like that anymore, you know? People are very open to it.

Similarly, for Karen:

A lot of people have got much more aware, not necessarily of spinal injuries, but of just wheelchair bound, physically unable people, the whole works. There isn't the stigma like there used to be...whether it's the fact that people don't end up shut away anymore, you have got a life...I suppose it's just the usual getting used to everybody looking at you to start with, but in the end I think you probably find that you worry about it more than other people, and then it just doesn't matter

Michelle appeared to feel more noticed in a wheelchair; nevertheless, like Rachel and Karen, she did not appear to feel discomfort from this attention:

People do notice you in a wheelchair, would be silly if anyone said they didn't. Like, children are the best, cause they just ask you questions straight out.

Overall, it appeared that Amanda and Karen felt the greatest discomfort with their bodies since the injury. While Rachel originally did experience some discomfort with her body due to lack of control, her rehabilitation experience appeared to have been more positive than Amanda and Karen's experiences. The only discomfort Michelle appeared to show with her changed body is her dependence on others; like Rachel, her rehabilitation experience seemed to be a more positive one.

The phase moving toward comfort consisted of a progression of strategies in response to the challenges imposed by a changed body (Chau et al., 2008). This progression was achieved first by social isolation, and eventually developed to portraying a positive representation of oneself through appearance and behaviour (Chau et al., 2008). Two women in this study, Karen and Rachel, appear to have advanced through this phase at some point. Displaying the social isolation common in the first progression of this phase, Karen commented:

> Karen: [My ex-boyfriend] came to see me in hospital about three months later, and I wouldn't see him. I couldn't physically look at him…I was still in traction, I hadn't washed my hair. I didn't want him to see me like that at all.
>
> Interviewer: Have you seen him again?
>
> Karen: No, never to this day. And I feel really bad about how he made the effort to come and see me in hospital…but it's like 25 years now, been long gone. But I couldn't let him see me like that…I didn't want his pity either.

Rachel also appeared to have a reduced social life following the accident, even though she claimed to have the same friends:

> It varies, I'll go out and do something, but I don't really go out very often I must be honest. It's sort of at the weekends with my sister…the thought of an electric wheelchair at the moment I just can't get my head 'round. You know, I can't imagine going somewhere by myself. And I think when I do walk, you know, get pushed around and everything, I do feel quite self-conscious.

The second part of the moving toward comfort phase is that of positive self-representation (Chau et al., 2008); this is often an attempt to preserve their pre-injury identity and body image. Once again, Michelle, Rachel and Karen appear to exhibit this aspect of moving toward comfort more than Amanda. Michelle commented:

> Interviewer: What would you say makes you feel most womanly or feminine?
>
> Michelle: Just getting your hair done and everything, your hair and your makeup on, put a girly top on and things

Similarly, Karen commented on how she felt when she would prepare for a ball:

> We used to do the whole hump ball thing…it was like, going into the hire shops to find [a gown]. I never thought that I could look good and *feel* good in a ballgown, you know…I've been to three balls then, I've been to a lot more since…it has worried me about how I will feel in it compared to everybody else…it's my only time when I say "right, this is it, I'm going to have my hair done, I'm going to have my nails done, I'm having a facial, this is my minute to be feminine". I thoroughly enjoy putting my dress on and feeling good…I know I'm going to be accepted by the people around me and they don't care, not about how I look, but about the fact that I'm in a chair.

Finally, Rachel summed up the positive self-representation phase when she said:

> I take pride in my appearance…I still want to make sure I look ok, and don't look scruffy…I think it just makes me more approachable.

The final phase of the process described by Chau et al. (2008) is comfort; this is attained when participants express a sense of ease with their changed bodies, and is characterised by participants' willingness to openly discuss issues related to living with an SCI in both familiar and unfamiliar environments (Chau et al., 2008). In this study, one context in which comfort is expressed is educating others. While this communion with others in a dyadic fashion is customary for a communicative body, the only participant who appeared to educate others to any extent was Amanda. Amanda frequently participated in 200-mile cycle challenges to raise money for charity, and also participated in other fundraising for spinal research:

> The day they take the photos [of the cyclists] I hate it because they stick the four wheelchairs in front and it's a big thing. But you cope with it, because it's a means to an end. We cycle to raise money for charity…so you do it.

The other context in which comfort is expressed is immersion within an accepting environment. This seems to be the most commonly exhibited phase in the process for all of the women in this study. Whether it is with family, or specific friends, all of the women have a certain social circle in which they feel comfortable and treated as 'normal'. Michelle commented:

> There's a couple of us have our birthdays together, so we always go for a Chinese banquet, well I'm just the same. I'll get my hair done…put my makeup on, buy something nice new to wear and I go out. It's the same as we would have done beforehand, we'd all get together in a big crowd so we'll go and have a banquet in between our birthdays

Similarly, Rachel said:

> I've got a lot of friends, but I've only got a select few that are very special friends…cause we were that small unit…it just hasn't changed, and obviously they're married and stuff now but…it's still just as good as we ever were really…that's the kind of friends I need

While Michelle and Rachel appear to have kept the same friends from prior to their accidents, Amanda and Karen had to rebuild their social circles; nevertheless, they now surround themselves in a new social circle in which they feel comfortable. Amanda stated:

> I've got two friends…I consider them more my family than my family…Dave is my next of kin, because he's actually my physio as well…and Jen is a friend that I've known for about thirteen years now…I have nobody from before the injury, including my family, that has really stood by me.

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Likewise, Karen commented:

> There was a group of about ten of us, having the summer of our lives. I mean, they say summer of '69, ours was summer of '89. It was great…our group of people are exactly the same as us, farmer types…we're much happier cooking a meal or going to somebody else's house than going out to posh restaurants. Whether I've just been exceptionally lucky, or whether they've just seen me for who I am and not what it was…I never felt at any point that nobody has accepted me, or been embarrassed by me.

Becoming comfortable with the changed body after a SCI is important. Discomfort with the body and negative body image can lead to unhealthy weight loss practices (Battle & Brownell, 1996), restrained eating (Paa & Larson, 1998), eating disorders (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1998), depression (Perlick & Silverstein, 1994; Pinhas, Toner, Ali, Garfinkel, & Stuckless, 1999; Wiederman & Hurst, 1998), and poor self-esteem (Tiggeman & Stevens, 1999). Chau et al. (2008) point out that "the physical changes associated with a spinal cord injury affect a person socially, emotionally, and psychologically" (p. 220). While there are many ways in which researchers can investigate these effects, one commonly used research technique is the study of narrative.

4.3 Narrative

As noted in previous chapters, the study of narrative is the study of the ways in which humans experience the world (Dhunpath, 2000). However, as Smith and Sparkes (2007) explain, "narratives are not conceptualized as unmediated representations of internal cognitions, as springing from individual mind, or as simply personal. They are social actions and drawn from cultural repertoire" (p. 26). Given that our personal stories are drawn from a cultural repertoire, just what stories do the women in this study draw on? In other words, what kinds of narratives do they appropriate from culture and then tell to help make sense of their SCI experience? One dominant type of narrative is the restitution story.

4.3.1 The Restitution Narrative

As explained in previous chapters, the plot of the restitution has the basic storyline: "yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank, 1995). In terms of spinal cord injury, this plotline adapts to

"yesterday I was able-bodied, today I am disabled, but tomorrow I'll be able-bodied again".

In their interviews with men injured via sport, Smith and Sparkes (2004; 2005b) found that the vast majority of their participants had a preference for this narrative. During this research, none of the women displayed a classic restitution narrative inasmuch as they sought continuity with their former lives, but did not pursue a former state of health. However, the idea of walking again was not completely ruled out. That is, elements of restitution still permeated their stories. For example, Amanda commented:

> Interviewer: How have things changed for you since the injury?

> Amanda: …Having had that experience I think has made me a better and stronger person. So I wonder what I would be like if I just got up and walked again tomorrow. You know, it would be interesting to see.

However, at no point in her story does she give a statement of her intent to walk again, and thus actively pursue a restitution narrative. Indeed, Michelle doesn't understand the desire to walk expressed by others:

> Michelle: We were always taught "you want your arms and hands, you don't want your legs"…you've got your arms and you've got your hands, you can do most things for yourself. But now, you listen to some of these younger ones and they're "I want to learn to walk". And I said, "you can't use your hands, you can't move your arms, what good's walking to you?"

> Interviewer: So you've never really thought about a cure?

> Michelle: Yeah, you do, you'd be stupid if you didn't…but it's not worth spending every waking hour travelling the country, when you know…it's not even a maybe yet, it's still very out of reach at the moment.

> Interviewer: Do you keep up to date on any of the research that's going on?

> Michelle: Yeah, spinal magazines, people at the hospital…you do keep your eyes and ears open…

Karen similarly commented on *others'* desire for restitution, and other people's strong preference for SCI people to walk again becomes a story she has to contest with – despite not believing she will ever walk again:

> You know, they all have this "I am going to walk again" and that's one of the things that's never…I don't know whether if I'd been a lower lesion, if there'd always be that hope in the back of my mind. I suppose I've always got used to the idea it's never going to happen in my lifetime. And I'm not

going to kid myself that it is. It ain't going to happen and that's it. You know, I severed my spinal cord, my neck is held together with a blinking coat hook, and I'm lucky that I can even hold my head up

Finally, Rachel commented on her version of restitution:

Interviewer: Do you ever imagine walking again?

Rachel: Oh God, yeah…but I don't hold out for a cure, at all. And I wouldn't put myself forward for something like that, I would be a bit scared. I mean, I was offered this thing a while ago, that they put something in your arm and it makes your arm move, and I just think I'd be a bit like…not wanting a foreign body, I just wouldn't want that at all.

For all of the women, one of the main aspects that seem to prevent them from fully embracing the restitution narrative is the question of time. Michelle, Karen and Rachel all comment on their belief that a cure is still out of reach, and give that reason as the basis for not actively seeking restitution. These women believe that the search for a cure – the time spent from getting research from the bench to the clinic – will not happen in their lifetime. Thus, for the four women in this study, it seems nonsensical to seek restitution. Sparkes and Smith (2003) found that men in the restitution narrative recount their life in the future as they wait for a cure that will return them to an able-bodied state of being. Thus, this research on women stands in contrast to the research conducted by Smith and Sparkes on men and SCI.

Accordingly, although all the women commented on thinking about a cure, none of the women told their stories in this manner, which indicates that none of them actually displayed the restitution narrative. This displays that while they have thought they would like to walk again, they don't think it will happen. Thus, they don't take on this narrative as a key way to shape their experiences of SCI. In other words, restitution has been a story that has permeated their consciousness, but they have decided not to take it on board (Frank, 2006). Nevertheless, one of the woman's' stories did have some similarities with the stories told by the men in Smith and Sparkes' (2004; 2005b) studies in terms of the connections with chaos and quest narratives.

4.3.2 The Chaos Narrative

According to Frank (1995), the chaos narrative is the opposite of restitution: its plot imagines life never getting better. He further explained:

> If narrative implies a sequence of events connected to each other through time, chaos stories are not narratives. When I refer below to the chaos narrative, I mean an *anti-narrative* of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself. Although I will continue to write of chaos stories as being told, these stories cannot literally be told but can only be lived (Frank, 1995, p. 98).

In addition, control and chaos exist at opposite ends of a continuum. Frank (1995) explained:

> The restitution story presupposes the control that is necessary to effect restitution. The ill person does not have this control herself, but those taking care of her do, which for the restitution story is close enough. The chaos story presupposes *lack* of control, and the ill person's loss of control is complemented by medicine's inability to control the disease. Chaos feeds on the sense that *no one* is in control. People living these stories regularly accuse medicine of seeking to maintain its pretence of control – its restitution narrative – at the expense of denying the suffering of what it cannot treat (p. 100).

In this study, out of four participants, only one participant showed any hints of the chaos narrative. It appears Amanda used this anti-narrative shortly after being injured, and continued with a chaos story for a significant period after returning home. The comments made by Frank (1995), of medicine seeking to maintain its pretence of control, came through in Amanda's story strongly:

> Rehab shouldn't be called rehab. It felt like able-bodied individuals go into this big factory as individual people, and at the other end of the factory on a conveyor belt come disabled people sat in a wheelchair. And they're all on the same drugs, that have the same life and the same carers, and absolutely everything prescribed by somebody else. And this somebody else has trained them and taken away any spirit and hope they've got, and has downtrodden them into thinking "this is the only life that's available to you".

In addition, this medical pretence of control, and Amanda's chaos led to her boyfriend of 2 years leaving her within a few months of the accident. This led her further into the chaos story:

> That was one of the hardest things, because I felt that I'd lost another part and I hadn't had a chance to prove them all wrong. He just listened to everybody else and made a decision…I felt he was taken away from me while I was disabled, while I was in hospital, and it was unfair, because I

didn't have a chance to prove everybody wrong…I was still weak, I was still at their mercy, I was still being dictated to. At that point, this was all around the time that I was telling my GP I wanted to die, that I was having "home-don't-care" looking after me, that somebody was deciding when it was convenient for me to go to the toilet. It was really the worst time of my life, and you just reach saturation point. And whatever else happens you just…have to get your head down and get through it.

However, Amanda was somehow able to reject this anti-narrative and find her way another narrative. Exactly how individuals shift narratives in relation to SCI is still unknown (Smith & Sparkes, 2005b), but Amanda believed it was her anger at her treatment that changed her view:

I was absolutely convinced that I was not going to live like that, and so I wanted to die. The only reason I'm still here is because there was nobody to assist me with suicide, because if I could have got the top off a bottle of tablets, I'd have done it. I gave into it, and I think when I came home and could see what was happening to my house…my house was getting dusty and neglected, and my life was just being taken apart bit by bit. And nobody looked after anything, including me, as I had. And I sort of just felt, well, if I was dead, if there was no hope, I wouldn't be feeling so angry, so irritated that everything's been taken apart. So I obviously still am the same person and that's when it started…I think it's just sheer hating being dictated to by other people, and being told by people that are less intelligent than me, that don't know me and have no insight into my life, how it's going to be. I really hate that.

Clearly, Amanda is not in the chaos narrative when she tells these stories. However, she gives indications that at a point soon after her injury, chaos did indeed control her narrative. The narrative she is currently in, that is quest, (see next section), adds sense and stability to the chaos she experienced, and her anger at her treatment, Amanda suggests, is what helped her leave it behind. Frank (1995) comments: "Exercising responsibility requires a voice, and the chaotic body has no voice" (p.109). For Amanda, anger gave her back the voice she lost to chaos, and allowed her to take back the control that had been stripped from her. Indeed, the voice she reclaimed helped her fight back for what she felt she, and others in her position, deserved. Of course, anger is not necessarily always a good thing. For example, bodies that are angry can do physical and/or symbol violence in relation to other bodies. These bodies dominate others (Frank, 1995) and risk turning on others and themselves. But, at least for Amanda, a sense

of anger at her treatment during the rehabilitation process and beyond helped stimulate movement out of chaos and into a different kind of narrative.

4.3.3 The Quest Narrative

According to Frank (1995):

restitution stories attempt to outdistance mortality by rendering illness transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend to it. 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 through the experience (p.115)

This is the only narrative which Frank (1995) described in which the "teller has a story to tell – it speaks from the ill person's perspective and holds chaos at bay" (p. 115).

After surviving the anti-narrative of chaos, Amanda was the only participant who displayed hints of the quest narrative. This is surprising, given that Frank (1995) believed that the communicative body is told in quest stories. In fact, Amanda was the only participant out of the four women in this study to show no strong affiliation to the communicative body. Thus, in this study, *the communicative body is telling a story other than quest*. Nevertheless, Frank (1995) commented that those telling a quest narrative often used metaphors of a 'journey' within their stories. Indeed, Amanda used similar metaphors:

It's like taking a wrong turning on a road, and if you could just backtrack and go down that road, it's just a few seconds away. And that was an overwhelming feeling…that I could see normal, I could see my life there, and I could see the parachute opening normally and this is what's happened, and it's just a few seconds away. And then it's a few days away and a few weeks away and a few years away. The point where it went wrong is a very specific thing for me, and that's the point where my life took a different turning.

Unlike the other narratives described by Frank (1995), the range of quest stories is so broad that further specification is useful; therefore, quest stories have at least three facets: memoir, manifesto, and automythology. However, Amanda does not display all three of the facets required in a quest story.

The first facet of quest, memoir, combines telling the illness story with telling other events in the writer's life; this can also be described as an interrupted

autobiography (Frank, 1995). In this facet of quest, trials are not minimised, but are told stoically, with no special insight claimed at the end. Amanda often displayed this first facet of quest:

> I thought that the fact that I was medically trained before my accident has had a big affect on how I've reacted to it. I've always been very active, I danced from when I was six years old. I did ballet, came home, hung my ballet shoes on the back of my bedroom door and got on the plane [to the USA]. I didn't actually come back into the bedroom until several months later when I was carried back in, and one of the first things I saw was my ballet shoes on the back of the door…being paralysed was the easy bit, it was coping with everything else!

The second facet of quest is the manifesto. According to Frank (1995) the truth that has been learned in these stories is prophetic, often carrying demands for social action. Amanda clearly presented this aspect of quest:

> [TV station] made a documentary about the pregnancy, and I went along with it because I felt it was important to document it…If they were going to do this, I wasn't going to go without a fight, and I was going to scream it from the rooftops. The country pay social services to act on our best behalf, and I was going to tell the country what they were doing.

Amanda's call for social action continues further in her fundraising efforts for spinal research and other charities, and also in her business, where she'd "like to train really good carers and send them to other people". Another aspect of this manifesto facet of quest is that those who tell manifesto stories do not want to go back to a former state of health, which is often viewed as naïve illusion. Amanda does not fully fit with this aspect, as earlier comments show:

> I look at people that are couch potatoes and don't do any sort of sport and abuse their bodies, and I think "if I just had a body that worked, I just wouldn't do that". You don't realise what you've got, but you never do until you've lost it…

Nevertheless, she does not actively strive for her former state of health, or search for a 'cure' for her SCI.

The final aspect of quest is the automythology. This is represented in the metaphor of the Phoenix, that reinvents itself from the ashes of its own body (Frank, 1995). Automythology fashions the author as one who not only has survived, but has been reborn; it reaches out, but its language is more personal than political (Frank, 1995). This, however, is the facet of quest that Amanda

exhibits little of. Although there are obvious changes in her life since the injury, she claims to feel no different within herself:

> I think my life if I hadn't been injured would have been very different, but I don't think I've changed…I've gained a lot of confidence as I've got older…it's probably not anything to do with the fact that I'm injured, it's just you gain confidence as you get older.

In the end, out of the four participants, only Amanda showed any strong affinity for any of Frank's (1995) narrative types, and even she did not match the descriptions of the narrative types as clearly as those in the study on men and SCI by Smith and Sparkes (2004, 2005). Accordingly, what kind of story *are* the other women telling? What kinds of narrative do they drawn on from the cultural repertoire available to them?

4.3.4 The Resilience Narrative

Because the majority of these women appear to exhibit no strong affinity for any of the three common narratives used in illness and disability, it seems that there must be some other narrative that they are using. In this case, I propose to call this new narrative the *resilience* narrative. Resilience has been researched mostly in children who have overcome adverse situations to lead fairly normal adult lives (Monroe & Oliviere, 2007). However, in recent years more research has been conducted on resilience in more varied situations (Edward, 2005; Miller, 2002; Patterson, 2002; Richardson, 2002). Nevertheless, there has still been little research done on resilience in relation to traumatic SCI (White & Driver, 2008), and none conducted specifically on women and SCI.

Here, the resilience narrative can be defined as a story in which the person 'bounces back' from SCI, quietly adapts to a new body, and is malleable in terms what types of self they perform. Importantly, what sets the resilience narrative apart from other narratives, like quest, is a plot in which people claim to continue on with their lives with a minimal amount of change. Their sense of self might be malleable (as I show later) and their bodies may sometimes commune with other bodies, but a person minimises the effects of SCI on other aspects of their life by 'getting on' with life. It may be a life they didn't choose, but he or she will be resilient, 'bounce back', and 'get on with life' with minimal fuss or change.

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Whilst all the four participants told a resilience story, this type of narrative was especially apparent in the stories told by Michelle, Rachel and Karen. For example, Michelle remarked:

> It's just like everything else, it's life, you just get on with it. You don't brood over it, you just get on with it, don't you?

Likewise, for Rachel:

> It's just something you sort of dealt with…it's not the end of the world…I think you can still give a lot more…I think you learn ways to adapt and changed and just deal with it really…Just live every day and get on with it…it's just some instinct really…it's not going to change, you know?

Furthermore, the resilience narrative can be seen in action in the following comments by Karen:

> You just learn to do things, you find the best way for you…I can't live my life one foot on the break…I do think that sick people are unhappy people and I'm not…I'm lucky I get out of bed in the morning, and I *want* to get out of bed in the morning cause I want to get on with my day with the horses and what have you…I'm lucky I'm a very strong person…there were several people…you knew almost instantly whether they'd cope with it or whether they wouldn't…whether they'd get on in life or whether they'd just shrivel up and become nobody.

Whilst the participants told resilience stories throughout the interviews, one of the main <u>differences</u> between the three participants who displayed a strong resilience narrative relates to family and social support. What helped three of the participants to adopt a resilient narrative related to the social support offered by the family. According to Zaider and Kissane (2007):

> The family is a crucial resource…Family members often serve as primary caretakers; they guide the provision of support for loved ones…actively participate in decision-making processes and serve as liaisons and proxy informants to healthcare practitioners. The journey of illness is thus a shared one, resonating powerfully across the family group (p.67).

Indeed, the three women who appear to be using the resilience narrative all had deeply supportive families and friends. Michelle's family adapted their home so that she would have a bedroom and bathroom downstairs, and her friends encouraged her to remain involved with horses. She replied:

> Interviewer: Who is there for you emotionally? Who is your support system?

> Michelle: My mum I suppose. My whole family and my friends…I think it's everyone, you just get on with things in life…the first [horse] trap that was

bought for me was off my friends as a Christmas present – [They said] "here you are, find yourself a pony because we're not finding a pony for you, you can do something yourself"…and that was the way I was treated by everybody

Karen's family also adapted their home so she could easily live with them. When she got married, her parents moved out and she remained in the adapted home with her husband. She commented:

I was exceptionally lucky in the fact that I'd got a very supportive family around me…when I came out [of hospital] my mum and dad were pretty good, and I'd got myself adapted, and I had like a flat piece down there, and then they lived in this half of the house. And I had my independence.

Rachel's family moved back to the UK following her accident to be closer to her. In fact, she lived with her sister for a number of years following her accident, and still lives close by:

Rachel: I'm lucky cause we're a strong family unit, and I have a lot of really good friends that are just there…[Family is] just really important to me. Mummy and daddy and Claire, they're everything to me, and I would be lost without them. With support as well as, you know, they've never treated me any differently…I'm a lot closer with my father now, he's very protective. And my sister…I think before I didn't really used to see my family. When I was [overseas] I was always out. Claire and I were in the same school and university, but we didn't really hang out together very much. So I see them a lot more now, and I'm a lot closer to them now, I'd say.

Interviewer: How do you think the relationship you have with your friends and family has affected your experience of spinal cord injury?

Rachel: it's made it a lot easier. I do put a lot of it down to my friends and family, that I got through it and everything like that. Definitely.

However, unlike the other three women, Amanda's family retreated from her following her accident. This may have affected how she told her story, and may be why she had more in common with the quest narrative than the resilience narrative:

There're some people that are born into a family that copes. And my family aren't those people…they just can't cope. And they dealt with my injury, and the way things are…by just running away, that's just how they deal with it. It's not that they're bad people, it's just that they are…I consider them weak…my family were absolutely terrified when I first came home, because everybody was saying "oh she'll have to come home, her family will have to…." And that absolutely terrified them…so the family was really grateful I didn't go home.

Finally, social comparison also seemed to have played a role in creating this resilience narrative. Social comparison "refers to relating one's own actual or potential characteristics to those of other individuals, which may have consequence for how individuals feel and for how they evaluate their situation" (Buunk, Zurriaga, Gonzalez, Perol, & Lopez Roig, 2006). For the women who told resilience stories, knowing that their lives could be much worse seems to help them stay positive. In social comparison terms, then, the women adopted a downward comparison style. For example, Michelle stated:

> Well just get on with it, don't think about what could have been, just get on with it…and always say, look around, there's always somebody worse off than yourself, there's always somebody to think "oh I'm glad I'm not like that"…I don't have to have a machine breathe for me, do I?

Similarly Karen commented:

> You know, never feeling sorry for yourself because there's always somebody far, far worse off than you. Far, far worse off, so again just making you strong I suppose…there was a girl in the bed next to me and she'd had a riding accident and was incomplete, a lot lower than me…What I can remember about her now is just whinging and whining the whole time, and her parents were trying to be supportive, but I hope I was never like that, because nothing was ever right for her, nothing.

This downward comparison in terms of helping them perceive that their situations are not so bad as other people's situations may have much to do with the creation of resilience within the women using this narrative. However, with only three participants displaying this new narrative of resilience, caution must be taken on this view. Nevertheless, the women's stories do offer us a great deal. They allow us to clearly see that there are other narratives being told after spinal cord injury, which may help us when examining other aspects of these women's lives, such as identity levels.

4.4 Identity

Crossley (2000) suggests that any valid portrayal of human selves and behaviours requires an understanding of the inextricable and complex connection between narrative and identity. According to Scott-Hill (2004):

> Identity is concerned with the social formation of the person, the cultural interpretation of the body and the creation and use of markers of membership such as rites of passage and social categories. As such, it

might be thought of as mediating between the personal, private world of everyday life and the collective space of multiple cultural forms and social relations: it is a pivot between the social and the individual (p. 87)

The importance of identity as a means of understanding the complex relationship between individuals, society and biology (Watson, 2002) has led to many sociologists being interested in the idea of disability identities and biographical disruption, as defined in the literature review.

As previously mentioned, one of the most well-known theories concerning the identity levels of the chronically ill was developed by Charmaz (1987). The identity hierarchy she proposed has also frequently been used in relation to traumatic events such as SCI, since Charmaz (1987) commented that the 'type and degree of the illness often figure in forming identity objectives' (p. 288). She went on to say:

> Personal and social meanings of illness in general and the experienced illness in particular, shape identity construction and definitions of stigma. Some persons aim for high identity levels, requiring much effort to *overcome* stigmatizing identifications and to live autonomous lives. Others aim for lower identity levels to *avoid* stigmatizing identifications, rather than risk more attention focused on themselves. (Charmaz, 1987, p. 299)

However, while Charmaz' (1987) theory of an identity hierarchy is often used in relation to traumatic injuries as well as long term illnesses, not all of the participants seemed to fit completely into this theory. Two participants, Amanda and Karen, appeared to show identity levels not specified on the hierarchy proposed by Charmaz (1987). These two participants did, however, display identities as identified in Yoshida's (1993) study on identity reconstruction following traumatic spinal cord injury. This particular theory on identity reconstruction following a traumatic spinal cord injury bases itself, not on a hierarchy, but on a pendulum. Yoshida (1993) explained:

> The pendular shape of identity reconstruction among individuals with traumatic spinal cord injuries represents an oscillation between conceptually distinct, but empirically overlapping types of identities which encompass the non-disabled and/or disabled aspects of self. Central to the pendular shape is the expression of identity reconstruction as a dual directional process (p. 220)

However, while Yoshida's theory was based around participants swinging through this pendulum of identity levels, none of these participants exhibited this oscillation.

They more closely aligned with a sense if identity in terms of levels. Therefore, I will be continuing to use the identity hierarchy proposed by Charmaz (1987) as my main template when discussing the identity levels of the participants in this study, and inserting some new levels into her hierarchy based on descriptions in Yoshida's (1993) theory.

According to Charmaz (1987) it is not uncommon for ill people to begin at the supernormal level in the identity hierarchy, then rapidly decrease their identity aspirations:

> Initially, these individuals wish to do more than before so that they can succeed in new areas and compete in new realms, in addition to all that they had ordinarily done earlier. They aim for a supernormal identity level. Then, as they discover that doing so is much harder than they anticipated, they scale down their aspirations to handling a life without the added competition and goals. At this point, they strive for a restored self. As further hardships develop, uncertainty and risk underlie their efforts. By now, they scale down their identity objectives to a contingent personal identity. Last, when an uncertain future persists, they settle for a salvaged self (Charmaz, 1987, p. 293)

This general spiral down the hierarchy, at first glance, would seem to have more in common with chronic illness than the sudden injury suffered by the participants in this study. In some instances, people can gradually raise their identity level as a result of receiving assistance and encouragement. Still others move up and down the hierarchy. However, in this study all of the participants did appear to slowly slip down the hierarchy as time passed following their injury. While not all of the participants aimed as high as the supernormal identity level from the start, every participant changed identity levels at some point, and this change was always in a downward movement through the hierarchy; therefore, I will discuss those identity levels displayed by the participants in hierarchical order from highest to lowest, beginning with the supernormal identity.

4.4.1 Supernormal Identity

According to Charmaz (1987), chronically ill persons who pursue supernormal identities "wish to reject the negative identifying images conferred upon them by illness" and instead "seek to construct a personally valued and socially credited identity in conventional worlds" (p. 296). In this identity level,

success values of independence, hard work, deferred gratification and achievement are most clearly visible. Charmaz (1987) states that there are four conditions for pursuing a supernormal identity:

> (1) the person had achieved a place in the external world through extraordinary achievement in the past; (2) the person defines another arena for attaining extraordinary success; (3) the person assumes that handling illness demands competition and struggle; and (4) the person believes he or she will lose what is most important unless supernormal efforts are made (p. 297)

Out of the four participants in this study, only one showed any affinity at all for the supernormal identity level – this person was Amanda. Amanda clearly shows her attempt to "reject the negative identifying images" conferred upon her by her disability when she stated:

> I wanted to commit suicide…over the next year I told my GP I didn't want to live like this. And what you're really saying is "I can't live the life you're telling me", not "I want to die". And that is exactly what I've done. If I'd have done what the establishment told me I would have to do, I would be taking lots of drugs now…I'd have bedsores, infections, things like that. I've had none of that, but I'm a tyrant about my own care.

She further displays her rejection of the negative identifying images of her disability when she said:

> Immediately people saw me as different…I didn't feel any different. I am a person, and this is my life…I haven't changed.

Amanda had met the first condition for pursuing a supernormal identity prior to her injury by achieving the junior champion title in 4-way skydiving competitions. According to Amanda, before her accident, "everything was skydiving". The second condition, in which she defines another arena for attaining extraordinary success, is less clear; for while Amanda keeps active, participates in 200 mile cycle challenges, travels the world and cares for her son, her foremost area of extraordinary success since the accident has been in fighting for her rights to proper care and support. She appears to meet the third condition, the assumption that handling SCI requires competition and struggle, more than the second. However, both are apparent when she said:

> I've always thought that whatever care, whatever equipment, whatever support you get should enable you, and a lot of it *added* to the disability. It made the disability bigger…I've fought tooth and nail to get the life I have now. Three years after my accident I had my son, and rather than support

me, Social Services took me to court and was going to take my child into care at birth, because they said I was too disabled to look after him. So then I had a fight that lasted virtually the whole pregnancy to keep my son...I've fought to not only employ my own carers, but to be funded, and...I've fought for funding for physiotherapy...Everything has happened in spite of social services care...instead of because of them.

Nevertheless, these comments also show us the things Amanda believes are most important – personal care and her son among other things – and her knowledge that unless she continues to fight "tooth and nail" she may well lose them. Therefore she meets all four conditions for seeking a supernormal identity. In addition, Charmaz (1987) states that those aiming for supernormal identities seek to construct ones that are not only personally valued, but also socially credited in conventional worlds. Amanda's extraordinary achievements seem to be aimed much more strongly towards obtaining a personally valued identity; however she also attains socially credited identities via her cycle challenges and volunteer work.

While Amanda indeed shows a strong affinity for the supernormal identity level, she also displays aspects of other identity levels. One of the other identity levels she exhibits is the restored self, which is the next level down in the hierarchy. Not only did Amanda lock into this self, the other participants also exhibited this sense of self – but with some key differences among them.

4.4.2 Restored Self

The next level of identity on the hierarchy is the restored self. People aiming for this identity level anticipate returning to their former lives and wish to construct a similar physical self (Charmaz, 1987). Unlike the other identity levels on the hierarchy, a restored self can take on three specific types: (1) the entrenched self; (2) the developing self; and (3) the assumed self.

All four of the participants showed an affinity for some type of restored self at varying stages following their accidents; however, there was one major difference. While there are three specific types of restored self, a common aspect of all of them is that the individual strives to attain a similar *physical* self from prior to the injury. However, none of the participants aimed to construct a similar physical self, which is one of the main aspects of any type of restored self. This is clearly shown in Karen's statement:

> I've always got used to the idea [a cure] is never going to happen in my lifetime, and I'm not going to kid myself that it is.

Similarly, Michelle said:

> I'm not into this…like you'll believe one day they'll have a cure, or they'll make you walk, or there will be something…but you can't live your life, just waiting for that.

Therefore, while I go on to discuss other aspects of restored selves that the participants displayed, none of them aimed for a classic example of a restored self as defined by Charmaz (1987). Nevertheless, all of the participants at some point mentioned that they felt they were the "same person" they always had been, which indicates feelings of continuation with their former lives. It may be that for women, the end goal of the restored self is not physical, but mental restoration.

The first type of restored self is known as the entrenched self, and represents patterns of action, conviction and habit built over the years (Charmaz, 1987). These unchanged patterns had been a source of self-respect before illness (Charmaz, 1987). In the years directly following her accident, Michelle appeared to have the strongest affinity for this type of restored self; however, both Amanda and Rachel also showed aspects of it. Amanda commented:

> I lived alone, miles away from my family or anybody, so I was very self-contained…my dad was a very practical person, he used to do everything that needed to be done to the house himself, and as we were growing up, he taught us all…so even when I moved into my home, I wired the lights, I wallpapered, I put the bathroom tiles on the wall….I took for granted the fact that I could do everything for myself, I didn't need anybody's help.

Amanda's attempts to be independent and self-sustaining continued in every way possible following her accident:

> When I employ people, they always say "what exactly will I be doing?", and the easiest way that I can explain it to them is "you'll be doing exactly what anybody else does, except that you need to assist me…you don't need to know how to do anything, because my brain and my mouth work just fine, so I'll be able to tell you how to do everything, I just can't physically do it for myself"

Similarly, both Amanda and Rachel commented that since their accidents, in their dreams they continue to walk. Rachel stated:

> I think the thing that's strange is when you dream at night you always dream that you're walking. I think I've only once or twice dreamed I'm in a wheelchair.

Amanda also commented on her dreaming:

> When you dream, you walk around in your dreams, because your body image is of a person walking around, it's not of a person sitting down. And I suppose I've never got used to this person sitting down because…maybe my image of somebody in a wheelchair and my image of how I am, don't match up.

Although Amanda and Rachel do not explicitly or consciously seek to lock into a restitution narrative in their verbal, conscious stories, perhaps these images of walking in their dreams might be an insight to Amanda and Rachel's *unconsciously* entrenched selves. Clearly, this is very speculative. But, these insights do allow us deepen our appreciation of Amanda and Rachel as complex human beings who not only tell stories in their waking lives to make sense of SCI, but also dream in narrative too.

Furthermore, it must be remembered that Michelle is the participant who appears to have the strongest affinity for the entrenched self in the years immediately following her accident. She commented:

> I had a secretary job…after I had my accident I still went back and worked for them for nine years…the horses are still there, so they need looking after

In addition, after leaving the hospital, Michelle returned home and was cared for by her parents. That situation has remained the same in the twenty-five years since her accident.

The second type of restored self is the developing self, where the person emphasises reconstructing his or her ability to shift and change as well as to explore new identities as possibilities emerge (Charmaz, 1987). Frequently those who emphasise the developing self have not yet become tied to identifying permanent commitments (Charmaz, 1987). Largely due to her age at the time of her injury, Karen, not surprisingly, showed the greatest affinity for the developing self. At the time of her accident, she was sixteen years old, had just finished school and was in the first few months of her chosen career path. She commented:

> When I reflect back, if there could ever have been a good time for it to happen in my life, it probably was then, because it was such a turning point, you know, from childhood to adulthood. I'd made no plans, I'd got nowhere in my life, there was nothing that was going to be interrupted…like I say, in reflection, when you hear about families being turned upside down, children

having to go through it, having got a career, then career getting completely smashed out the window...in a funny sort of way, it probably happened at a good point in my life, because then I could pick up and carry on.

This undeveloped sense of self possibly allowed Karen an easier transition following the accident. Because she was in a new environment, making new friends and attempting to adapt to a new situation, this adaptation was simply able to continue following her accident. However, with the exception of Michelle, all of the women, regardless of their age at the time of the accident commented on the fact that one never knows what their life would be like; therefore it was impossible for them to say exactly how their lives differ from what it may have been. Amanda's response to how things have changed for her since the accident is similar to what Karen and Rachel also said:

> Interviewer: Has anything dramatically changed since having the injury?
>
> Amanda: It's hard to say, because you don't know what your life would have been like otherwise.

While for Karen this sort of comment might be put down as a sign of an undeveloped sense of self, it is unlikely that all three of these women, at such differing ages at the time of their accidents, would lack a fully developed sense of self. For Amanda and Rachel, this is the only hint of a developing self that they exhibit; however, Karen's affinity for the developing self continued further.

Karen further displayed a developing self in her ability to shift and change. Throughout her story she emphasised her ability to adapt to her new situation:

> It's just, you know, adapting to everything. You know, silly things like you put the kettle on something that's higher than it and it tips into the cup alright…I mean, the only thing that we've ever had in the house here is the slope there [into the kitchen] so I can get down to the washing machine, and the lift. Everything else is more or less as it would be…I remember spending a whole day in court arguing whether I wanted an electric toothbrush or not…I don't need an electric toothbrush, somehow I manage to wedge my toothbrush in my fingers and I can use a normal one. Nowadays everybody has an electric toothbrush, but I don't, and I don't want an electric toothbrush.

Karen showed further adaptation as she went on to say:

> I don't need the riding – I thought I would but I don't. Just being involved with horses is enough for me

The third type of restored self is known as the assumed self, where individuals have constructed typically unstated and taken-for-granted assumptions through habits and customs about who they are and what their lives mean. Who these people "really" are can be discerned only in their own social milieu (Charmaz, 1987). Out of the four participants, only Michelle and Rachel showed any affinity towards an assumed self. This is likely due to the social support that they had at the time of the accident, which has continued until the current time. Both Michelle and Rachel relied heavily on family support immediately following the accident and even now. However, as has already been mentioned, Amanda's family retreated from her following the accident. In addition, while Karen's family was highly supportive following her accident, they stepped back in their support once she was married and living alone with her husband. Michelle clearly displayed the social milieu which helped define her sense of self with her horse riding, which became carriage driving following her accident. She said:

> I still do a lot of riding for the disabled, we do that on a Thursday afternoon. I train with one of the groups. We also belong to different driving groups, so there's always lots of jobs like that to do. I still go and watch the show jumping, but I don't get very much time for that.

In these comments, Michelle shows how much her social life revolves around horses and driving. In addition, the way she switches between "I" and "we" when telling her story points out another aspect of the assumed self – a merging of her identity within intimate relationships. In this case, that merging is with her family, and in particular her mother. Rachel also shows some of this aspect of the assumed identity, in her close relationship with her own family, and in particular, her sister:

> Interviewer: What does family mean to you?

> Rachel: They're just really important to me. You know, mummy, daddy and Claire, they're sort of everything to me. You know, I would be lost without them. [Claire has] sort of been there a lot…she's been great for me, and if it wasn't for her I think things would be very different.

It is clear that at some point or another after their respective accidents, all of the participants displayed an affinity for at least one, if not multiple types of restored self. However, for all of them, this was only one of a number of different identity levels that they have experienced since their injuries.

4.4.3 Disabled Identity as an Aspect of the Total Self

This is the first of the identity levels described by Yoshida (1993) that I insert into the identity hierarchy proposed by Charmaz (1987). Karen, and to some extent Amanda, appeared to be the only people in this study who exhibited this identity level. That is, for these women, the disabled identity represents one aspect of the person, as opposed to encompassing or nearly encompassing the total self. People, like Karen, in this stage of the identity hierarchy considered both their non-disabled and disabled aspects of self, in varying proportions. Karen shows this when she said:

> Luckily, two or three years later, they decided to do a bladder implant on me, and that worked and that was the best thing I'd ever done and ever had in my life. No more catheters, no more leg bags, but I do have to plan everywhere I go and everything I do, with whether they have a disabled loo.

The bladder implant allowed her to feel less disabled again, by getting rid of the leg bag and catheter; nevertheless, she still needed to acknowledge the disabled aspect of her self with the planning she was required to do in regards to facilities. In addition, she clearly shows that she has not yet reached the middle self because she has not yet accepted the level of dependency in her life:

> I do wish I had my independence a little bit more…if I go to a show Aaron is always with me, if we were moving lorries, I couldn't drive those anyway. My sister's house, I can't get in because she's got another ten steps up to it…we don't go there very often at all

While Amanda does not actively display this identity level, it appears that she may have exhibited it at some point since her injury:

> When I broke my neck I didn't know how to switch a computer on, and I was just trapped in my living room, because I couldn't get out of my living room. So it was either learn to use a computer or watch daytime TV. So I'm quite good with computers now.

From these comments, it seems that Amanda was attempting to consider both non-disabled and disabled aspects of her self. While she felt "trapped" in her living room because of her disability, she also gave consideration to her non-disabled self because she did not want to give in to watching daytime TV. While this is one of the few hints that at some point, Amanda possibly exhibited characteristics of the disabled identity as an aspect of the total self, it seems likely that this was indeed one of the identity levels she reached. All of the participants in this study

changed identity levels at least once, and each one moved down the hierarchy. Amanda appears to have changed identity levels more times than any other participant before finding a stable identity. While she started at the top of the hierarchy, with the supernormal identity, she slowly slipped down it, finally coming to rest in the following identity level: the middle self. Because she passed through the restored self, it is logical to assume that she also passed through the disabled identity as an aspect of the total self on her journey to the middle self.

4.4.4 Middle Self

Amanda is the only participant in the study to display characteristics of the middle self as described in Yoshida's (1993) work. The middle self incorporates three traditional elements: (1) the individual understands that s/he is in a wheelchair and this is the way it is and will be; (2) the individual understands there are limitations associated with having a SCI and does not view them as negative; and (3) the individual has a 'collective disabled unconsciousness', which is a consideration for others with spinal cord injuries or people with disabilities, in decisions s/he makes with respect to social interaction and everyday life (Yoshida, 1993).

Amanda clearly demonstrates all three of these traditional elements. In relation to her understanding that she is in a wheelchair, she commented:

> We'll make a joke of the fact that I'm in a wheelchair…We all went to the Rocky Horror Picture Show, and somebody said "what did you go as?" and I said "well I went as the professor because I already had the prop!"…I don't want people to ignore the fact or not mention that I'm in a wheelchair…the things I like haven't changed….I miss dancing more than I miss walking, but there's nothing that I can do about it

In addition, her understanding of her limitations and acceptance of them is also unmistakably evident:

> The fact that the girls have been trained to do everything for me has made me so independent because I can go anywhere, you know. I can go abroad, I can go cycling in the middle…and whoever's with me will know how to change a catheter, if I choke, will know how to do an assisted cough, can deal with dysreflexia, can deal with any eventuality…There are some carers now that are trained to do bowel care and things to help people be more independent, but the district nurse still has to change their catheter every three months and it's like…they don't have to do that! And I always say that my carers do things with a lot better technique than any of the

medical professionals that have ever done it. And it makes me completely self-contained.

These comments clearly show that Amanda has accepted a level of dependence in her life and doesn't view it as negative. However, in her mind, her 'dependence' on her carers is really 'independence' from the district nurses and home-care usually used in these situations. She almost views her carers an extension of herself, because they do things according to her instructions. Thus, in a sense, dependence takes on 'new meaning'.

Finally, Amanda also displayed a 'collective disabled consciousness'. She not only raises money for spinal research, and does 200-mile cycle challenges to raise funds for charity; she has also become a social services provider herself:

> I ran my own care package for so long, and then two years ago my physio actually was looking after another guy who needed the same sort of care package as me. But because it's direct payments, and you have to employ your own staff, he couldn't do that, so then I started running two care packages. And because I was doing that I had to become an official business and get insurance and get registered with social services, so now I'm actually a social services provider, but a good one!

While Amanda finds the middle self to be a stable identity level for her, other participants slipped lower on the identity hierarchy. Michelle, who began at the identity level of restored self following her accident, appeared to have skipped the two intervening identity levels and passed right onto the next level in the hierarchy: the contingent personal identity.

4.4.5 Contingent Personal Identity

The contingent personal identity (CPI) is the third identity level on Charmaz' hierarchy, and the fifth on this proposed hierarchy for women who have suffered an SCI. A level of precarious health leads to viewing identity goals as uncertain, and those who aim for this identity level see SCI (or illness) as posing the primary risk of failure rather than failure resulting from their own efforts, as do those who aim for a supernormal identity (Charmaz, 1987). According to Charmaz (1987),

> people implicitly or explicitly settle for a contingent personal identity under the following three conditions: (1) when they believe their illness may dramatically alter their lives; (2) when they accept a less-valued self than that held prior to illness because of the intrusiveness of illness in their lives;

and (3) when their plans fail and they lose hope of attaining either a supernormal identity or a restored self (p.p. 308-309)

In this study, two participants showed an affinity for the contingent personal identity at some point after their accidents: Michelle and Rachel. The reasons for this are uncertain, due to the participants themselves seemly not knowing; however, these two participants were the most reliant on their families for support, which may indicate external influences on their long-term decisions. For Michelle, her transition from a restored self to a contingent personal identity seemed to begin about nine years after her injury:

> I decided I'd finish work, because work was changing, the job was changing, and it was getting faster. It was all to do with, like the new computers were coming in and that meant the pressures were different…I was working and not doing anything else because by the time I got in from work I was too tired

These comments show the dramatic effect Michelle felt her injury was having on her life, and the intrusiveness. However, there appear to have been further factors in her transition to a CPI – a recurring shoulder injury, from before her SCI, caused her to give up some of her new activities:

> It's an old shoulder injury…before I had my accident I'd dislocated it – it used to come in and out a lot. When I had my accident, they were a bit wary about doing anything in case it made things worse, so I used to just pop it back in…so then I was driving and just parked the car and put my arm on the steering wheel, turned around to look for my friend, case I was meeting them in the car park, and my arm came out and I couldn't get it back in. So that's when they took me to hospital and sorted me out, so now I'm just taking things easy with it…I had to give up the rugby and the table tennis

However, this assessment of time may not be related specifically to the contingent personal identity. While Michelle's assessments of time led her to believe that her chances of attaining a preferred identity are uncertain but conceivable (Charmaz, 1987), other participants also used assessments of time to settle into differing identity levels in the hierarchy. In fact, a certain amount of time assessment comes through in all of the participants' stories; however, Michelle's comment is a good example of what all of them mentioned:

> One day they'll have a cure, or they'll make you walk…but you can't live your life, just waiting for that

As previously mentioned, Rachel also displayed an affinity for the contingent personal identity; however, unlike Michelle, who first aimed for a higher identity level and then slipped down the hierarchy, Rachel seems to have aimed for a contingent personal identity from the start. Based on the data generated, and in her own admission, it is uncertain why she aimed for such a low identity level right from the beginning; but it may have been due to the effect the accident had on her self-confidence:

> I think my confidence has decreased since being in the chair…I just sort of never had it since being in a chair…I can't imagine going somewhere by myself…I think personality-wise I haven't changed, but confidence has definitely changed.

However, once again, external influences from family members may have affected her belief in her abilities subsequent to her SCI:

> My rehab and everything, I didn't really put stuff into it. I just was…I'm very nervous in my chair…I was very worried about falling out of my chair. Getting onto the balancing bed, or whatever it's called, I just couldn't do it. I think I might have spent a couple of times on it, but was just like in tears and wanted to get off. Then just sort of came out and prepared to just living…I had a flat, [but] it was on the third floor, so I had to find somewhere to live. So we found this place and I moved in with my sister, cause mum and dad were still [overseas] and I obviously couldn't go back there anymore, it just wasn't feasible really with the wheelchair.

For Rachel, it seems as though only the first two conditions for a contingent personal identity are met. The third condition, where failing plans cause one to lose hope of attaining supernormal or restored selves, never seems to have occurred. Starting during her time in the hospital, Rachel seemed to have come to an acceptance of a less-valued self than that held prior to the SCI. She stated:

> Job-wise and things like that, I think that sort of diminished with it. You know, I would like to work, but it's just like, what work could I do? And you know, sort of getting up every morning, sometimes it just doesn't happen according to plan and things sort of throw a spanner in the works, so I just couldn't….

In addition, her fragile hopes to work extend to her leisure time activities as well:

> Sometimes I just think "oh I'd love to go and play tennis" or you know, horse riding, I miss that. You know, I'd love to go and do horse riding, but I could just imagine getting all excited and falling right off the other side

Nevertheless, neither Michelle nor Rachel seem to stay at the level of the contingent personal identity for long. As time went by, both dropped down to the

final identity level on the hierarchy: the salvaged self (Charmaz, 1987). This may be due simply to the amount of time that had passed since their accidents – after years with no improvement, and in Michelle's case, setbacks due to further injury, the hypothetical possibilities of the contingent personal identity slipped further away, and left them struggling to find a stable self.

4.4.6 Salvaged Self

The salvaged self is the final and lowest identity level on the hierarchy (Charmaz, 1987). Aiming for this identity level means attempting to maintain some positive past self images as good and worthwhile despite the adverse circumstances in which these people find themselves (Charmaz, 1987).

People generally attempt to salvage prior self-images at two turning points in the chronology of their SCI or illness: (1) when ill people initially recognize marked losses of self due to SCI or serious illness and; (2) following cycles of immobilization when disabled or ill (Charmaz, 1987). For Rachel, her descent into the salvaged self seems to have occurred at the first turning point, when she initially recognized marked losses of self, relatively quickly following her accident. At this stage, she seems to have attempted to maintain a positive self-image through her social life, her belief that she is still living her life the way she chooses, and her hopes that she will eventually find something she wants, and is able, to do:

> I think I do live my life the way I want to live my life, and I'm very happy. It's not like I go, 'oh I wish I would…'. Obviously I would like to work, I would like to get out and do a job, but I do live a very full life and I get out and socialize a lot, so I'm not bothered about all that sort of stuff…I just don't know what I actually want to do…it's just finding that, what I want to do, and getting it and doing it. So one of these days I'll figure out what I want to do in life, and go for it.

In spite of this, Rachel was unable to fully maintain a salvaged self. According to Charmaz (1987), chronically ill persons, or disabled people, occasionally become so preoccupied with their losses that they cannot salvage any kind of positive self-image – their losses consume them. Rachel shows her difficulty in preserving a positive self-image:

> I feel quite lazy. I'm not striving to do more…I don't want to make a fool of myself, put it that way. You see people doing amazing things, and I think to myself "God, Rachel, if they can do that, why can't you?', but it's just like

the confidence thing again, holds me back…I'm just scared to do sports and everything, and I just think, "well what can I do?". And I know that's a negative way to look at it, but I do kind of think…"I cant feed myself…if I was to go shopping I couldn't get anything off the shelf"…I've just sort of accepted that this is it.

For Michelle, her fall to the salvaged self appears to have occurred during the second turning point, following cycles of immobilization when disabled or during illness. Once she reached the stage where work was all she had the energy for, she retired from work in order to concentrate her efforts on the horses. At this point in time, she had reached the contingent personal identity; however, her fall down the hierarchy continued once she injured her shoulder. This led to her being "so immersed in [SCI] that [she could] not readily claim other identities in the external world. Consequently, [she turned her] attention toward carving out a tolerable existence in [her] present circumstances" (Charmaz, 1987, p. 311). Michelle stated:

> Now I'm mainly carriage driving for myself, and say judging, stewarding, and also do a lot of work with the driving for the disabled…and like, the RDA (riding for the disabled), you've got people coming that need your help, and your expertise to teach them. And even cause I'm sitting watching things, I mean I'm not hands-on as much, but the little things you miss…I tend to notice everything, I might notice there's a strap out of keeper or something silly like that.

In addition, Michelle finds comfort in trying to help herself and still doing what she can, however restricted she may be (Charmaz, 1987).

> Interviewer: Are things more difficult now, as you're getting older and your mum's getting older? Are you both having any more troubles with being dependent on each other?

> Michelle: No, cause we just…there's thing I can do for mum, and there's things mum can do. We don't do as much hooliganing and things that we used to do, but we just…you adapt don't you? Like everyone in life as they get older. Like dishes that go in the oven, for mum they've got to be lighter ones, not the old fashioned big heavy dishes. Jars that we can't open, we'll just leave that out and when Debbie or anyone calls, they'll open. Which is just like anybody else isn't it? No different.

As each participant has moved through the hierarchy in an attempt to find a stable, sustainable identity level, another common issue was commented on in all of their stories: that of dependence and independence.

4.5 Dependence and Independence

Independence is generally considered to be something disabled people desire above all else (French, 1993). Indeed, becoming dependent on others following an injury is one reason for feelings of discomfort with the changed body (Chau et al., 2008). However, independence, like disability itself, means different things to different people. The most common definition of independence in relation to disability is that of physical independence. According to Oliver (1993):

> in common-sense usage, dependency implies the inability to do things for oneself and consequently the reliance on others to carry out some or all of the tasks of everyday life. Conversely, independence suggests that the individual needs no assistance whatever from anyone else…in reality, of course, no one in a modern industrial society is completely independent, for we live in a state of mutual interdependence. The dependence of disabled people, therefore, is not a feature which marks them different *in kind* from the rest of the population, but as different *in degree* (pp. 50-51).

This definition is often known as the "self-care activities" definition of independence, and is often used by medical professionals. Indeed, the women in this study often used this definition of dependence and independence when asked about the changes they have needed to adapt to since their respective injuries. Michelle explained:

> Interviewer: How have things changed for you since the injury?
>
> Michelle: Well that you've got to be dependent on someone…I do need help…you need to ask someone to do things.

Rachel also commented on dependence in aspects of her life now:

> I find it hard having people around all the time, I used to like my own company…I taught the carers to do [my] makeup…it can be frustrating, cause you know how you do things yourself…cause sometimes people are a bit heavy handed…but I think once they've done it a couple of times, it's like, just let them get on with it now.

Karen similarly struggled to come to terms with the limits of her physical dependence:

> And I really struggled…I came home and we tried with the transfers and we tried with this and that and everything else, and in the end my mum and dad got to the point where it was like "this is just hopeless", you know. For two or three things that you can do, you're then spending a week in bed because you've just knocked your own skin or what have you…the pressure sores are rammed into you…I can remember being [in hospital] and these people going around in trolleys upside down…and that was the

one thing I was never going to do. I was never going to spend my life on my front with my ass in the air because I'd got a pressure sore…you physically want to do these things, you want your bit of independence back. I wanted to be able to get myself up in the morning, I didn't want to have to lay there until somebody came to get me up…So you try incredibly hard, but when it doesn't work, it really gets you down. The constantly back in bed made me feel like a bit of a failure…

Karen further commented on the creation of dependence within the medical community:

And the district nurse doesn't come in until nine o'clock, I don't want to be in bed at nine o'clock!...it's not just the spinal side of it, you talk to the elderly care and it's the same…you hear about these old people having to get up at nine o'clock in the morning and then having to go back to bed at four o'clock because that's the only help that's available to them, and I think that is very wrong.

These comments help to show how disabled people are offered little choice about aids and equipment. In addition, times at which professionals can attend to help with matters like toileting, dressing, or preparing a meal are restricted, and the limited range of tasks professionals can perform are further limited because of professional boundaries, employer requirements or trade union practices (Oliver, 1993). This, in turn, can have many negative consequences on a disabled person's psycho-emotional well-being, sense of self and body-self relationships. Indeed, Amanda made similar observations which demonstrate the impact of dependence and a "one fits all" model to disability on psycho-emotional well-being:

The moving and handling regulations, that's a big thing that actually hampers your activities in Britain. Uh, Regain, the charity…they're actually just for sports injured tetraplegics, they sent me a bike. But moving and handling regulations say that the carers can't lift me into the bike and I have to be hoisted into the bike. Which is fine, we can bring the bike [inside] and hoist me into it. But the bike's so big we can't then get it out of the room. So technically I'd have to be lifted into it in the garden, which means they can't really lift me into it because there isn't a hoist in the garden, so I can't use it. So it's rubbish. My physio helps a lot cause he just picks me up and puts me in things…he helps me to overcome a lot just by picking me up and throwing me over things that lifting and handling regulations say he's not supposed to do.

Even though both women struggled with the dependence forced upon them by the medical community, both Karen and Amanda eventually came to view physical independence as being secondary to being independent in other aspects of their lives. This, in turn, has a series of consequences in terms of their emotional

well-being, as well as their freedom of thought and action. As French (1993) explained:

> Narrowly defined independence can give rise to inefficiency, stress and isolation, as well as wasting precious time…an over-emphasis on physical independence can rob disabled people of true independence by restricting their freedom of thought and action (p.47)

Karen goes into detail:

> At the end of the day I view that my day is more important than getting up or going to bed and being able to put my trousers on myself. Being able to make sure the washing and the ironing's done and there's a meal on the table tonight, is more important than me being able to put my trousers on one day and then spend a week in bed and not being able to put a meal on the table and the washing…and it probably was one strong, hard thing to get used to, was losing that bit of independence but to gain other things. But that makes me more normal, that I can do all the normal wifely, motherly things.

While these comments show how Karen eventually learned to put her physical independence behind other aspects of her life in terms of importance, it also demonstrates how closely associated the pressure to appear 'normal' is with the pressure to be independent. While Karen has overcome the pressure to be independent, it appears that the pressure to be a 'normal' wife and mother are still present. All the same, Amanda, like Karen, also overcame the pressures to be physically independent; because both of these women remained higher up on the identity hierarchy, it may be that positive identities and self-esteem relate to overcoming pressures to be physically independent. Amanda now views her independence in terms of being able to be in control of, and make decisions about her life:

> When I employ people they always say "what exactly will I be doing?", and the easiest way that I can explain it to them is "you'll be doing exactly what anybody else does, except that you need to assist me to get up, get out of bed, get dressed. I need assistance with bowel and bladder management, and I need help around the house. You don't need to know how to do anything because my brain and my mouth work just fine, so I'll be able to tell you how to do everything. I just can't physically do it myself…I feel just as if I were able-bodied, it's just I find different ways of getting things done…the fact that the girls have been trained to do everything for me has made me so independent because I can go anywhere. I can go abroad, I can go cycling…and whoever's with me will know how to change a catheter, if I choke will know how to do an assisted cough, can deal with dysreflexia, can deal with any eventuality. And that's no big thing, you don't need a medical degree to do that, yet there's some ownership that nurses and

doctors have…I always say my carers do things with a lot better technique and a lot better than any of the medical professionals that have ever done it…It makes me completely self-contained.

Amanda clearly demonstrates that her independence is not linked to doing things alone or without help, but by obtaining assistance when and how she requires it (Morris, 1993; Oliver, 1993; Reindal, 1999; Rock, 1988). Therefore, for Amanda, independence is promoted as a "mind process not contingent upon having a normal body" (Huemann, quoted in Crewe & Zola, 1983). Nevertheless, there are still other aspects of independence, not related to the physical body or the thinking mind. For example, Karen mentioned financial independence during the course of her interview:

> I mean, things that worry me a little bit…we just don't have access to money…everything's made so much more difficult…I don't know if you know what horse boxes are like, but all horse boxes have what we call a living in the front, like a caravan. How're we going to do that with me? That's going to cost us a fortune and we don't have a fortune, so do I not go to shows? Whatever way we look at it, it's going to cost. And that's what annoys me so much about the accident, is everything costs so much more. And the money I was given twenty years ago is way gone, because they just don't take in the cost of inflation and what have you. We've squandered none of it…we bought a property, and the usual chairs and what have you…but you don't realise this when you're going through the court case, so that money isn't available, it isn't there, and it does stop my life. I've just had one of my benefits stopped because according to them I'm working. I *am* working; I don't disagree with them, to a degree. I'm working, but if I was able-bodied I wouldn't have to pay [another employee] to do what I can't. I'd be doing both. It's not the same, I cannot get out there and do what I have to do…which is where my business fails all the time, because it's almost having to employ two people instead of one. And that's what you can't get through to people, that everything costs so much more. I'm one of these people that I don't have the blue badge, I don't want to park in a disabled spot, I don't ring my health officer every time I need something, I don't need a special mattress, I don't need all your…I can cope without it. But it does make you very bitter to the fact that, hang on, I've probably saved you a fortune…you know, the fact that I could have a district nurse in here six days a week but I don't…I should have my home help here helping me clean, but I don't want that, I want to have the dignity of looking after my own house…I know what will happen is [I'll] probably break myself with another loan, but I shouldn't have to do that. But then, that's no worse than any other man or woman struggling to finance what they want to do either, to a degree. But it is harder, you know. Things are harder.

While there may be many varied aspects of independence in everyday life, it is an inescapable fact that they are difficult for disabled people to attain. Whether

it is their own physical limitations, dependency forced on them by the structure of the society they live in, or excess financial burdens, disabled people are expected to cope in a way not expected of other people (French, 1993). This, in turn, may have had a significant impact on the well-being and self-esteem of the women in this study. As noted earlier, for the women in this study, dependence on others created a significant discomfort with their changed bodies (Chau et al., 2008). Related to the issue of dependence, another difficulty the women in this study faced was how to approach intimate relationships and motherhood.

4.6 Relationships and Motherhood

Having intimate relationships and becoming a mother are goals often taken for granted by able-bodied women. Waxman (1991) contends that the disability movement has not adequately addressed disabled women's sexuality as a political issue, although "many of us find sexuality to be the area of our greatest oppression…we are more concerned with being loved and finding sexual fulfilment than with getting on a bus" (Waxman, 1991, p. 23). These 'reproductive rights' are described by Morris (1995) as:

> Having sexual relationships (whether they are heterosexual or lesbian relationships), family relationships, bearing and rearing children and making a home – all these are important to human and civil rights which, if denied to non-disabled women, would be the subject of outrage (p. 76)

Reproductive rights are also important because social isolation, limited opportunities to establish satisfying relationships, and emotional, physical and sexual abuse can lead for some people, but certainly not all, to problems with low self-esteem and depression (Nosek, Howland, Rintala, Young, & Chanpong, 2001). While all of the women in this study had varying experiences in relation to reproductive rights, these contrasting experiences help to show us the wide assortment of barriers and issues disabled women face. Of the four women in this study, Amanda was a single mother, Karen was married with a child, and Rachel and Michelle were single.

It has been pointed out that while:

> most able bodied women experience problems in being treated as a sexual object…many disabled women experience being treated as an asexual object…[and] may never have had the experience of flirting…being

harassed, or objectified" (Cole, 1988, p. 32; also Fine & Asch, 1988; Finger, 1984).

For example, Amanda explained:

Interviewer: What makes you feel most womanly or feminine now?

Amanda: People's reaction to me, really…I've got a very good male friend…and the fact that he and his wife treat me as completely normal is a big thing. I suppose men's reaction to me, is what I'm saying. If they treat me normally than I haven't got that obstacle. So I suppose the thing that makes me feel most feminine is when other people see me as a woman.

Interviewer: how often do you find that people don't [see you as a woman]?

Amanda: Oh…fifty percent of the time? I would say, roughly.

Interviewer: How does it make you feel when people meet you and don't see you as being a woman?

Amanda: The cripple in the chair. It's annoying and saddening, but I also think, "well it's their loss". But that's probably a conclusion that I've come to over the years, it would have upset me more in the early days I think.

However, the other women in this study did not feel they were treated as asexual objects. Karen replied:

When I first got together with my husband…luckily we've got a very open relationship and all the rest of it. It's like, wouldn't you like a woman that can wear sexy underwear? And his words were "it's not quite the same putting it on as taking it off". It's never bothered him, it probably bothers me more than it bothers him…No, I can't stride into a room looking tall and sexy and having set up the candles and all the rest of it…but as I say, it probably bothers me more than it bothers him.

Karen further commented:

I felt like [Aaron and his mother] had accepted me. I never ever felt like if I went home they'd shut the doors and ask "what are you doing with her?", it really didn't matter…He never ever made me feel like that. It's always, I am who I am, and that's all it ever was. Never felt like he was embarrassed to be seen with me or that we couldn't go somewhere because he wouldn't want to be seen…around a show with me in a great big wheelchair.

Similarly, Rachel replied:

Interviewer: Do you ever get the impression that other people don't really look at you as a woman anymore?

Rachel: No, I don't. I hope not!...I don't think they see me as different to like, a 'normal' person, someone else…they don't even see the chair, and just sort of see me I guess

However, even though they feel others perceive them in the same manner as before they were injured, Michelle and Rachel are not interested in seeking out intimate relationships. Michelle stated:

> Interviewer: Do you date at all?
>
> Michelle: No. I did do, I wouldn't now.
>
> Interviewer: Why is that? What do you think is different that you wouldn't date now?
>
> Michelle: I like to have loads of friends. I like friendships and nothing more, because I'd be asking them to help me and I don't like that. I like friends where I can say "well I'm going somewhere, do you fancy coming with me?"…which is much nicer than, oh I don't know, arguing and 'oh can you do this' and 'can you do that', or 'I need this doing'. You know, all the other things that you don't want to do while you're out and enjoying yourself…no, I think friendships are better…you want to be able to go out and enjoy yourself, you want to *enjoy* that. You don't want to burden them…you laugh and joke…not have the added arguments and the do's and the don'ts or I can't be bothered…

Thus, for Michelle, it appears she avoids relationships so that she won't "burden" anyone outside of her immediate family. In addition, she seems to feel a relationship would add unnecessary complication and conflict to her life. While some of Rachel's reasons for not seeking a relationship were similar to Michelle's, she had other reasons that contrasted:

> I find it hard, like with men, you know I don't think it's gonna…boyfriend and stuff like that, like sex and stuff, I just can't really see it happening. I don't know if I'll ever be ok with all of it, I just can't get my head around that…I did kind of have a boyfriend the other year, but it was just too stressful. I just wasn't ready for it…I think it was just my attitude towards it. I'd just be like "why do you want to be with me?", do you know what I mean? I just couldn't understand it, and I couldn't get my head around it, so I don't think I dealt with it well at all…I just don't see myself…men never see me that way, I'm a bit more hard work than they need really.

Therefore, while Rachel also seemed to think a relationship added complication to her life, and was "too stressful", most of her issues in seeking a relationship appear to be linked to her low self-esteem.

Amanda, like Michelle and Rachel, avoids intimate relationships. However, Amanda had a number of very different reasons for avoiding a relationship. While she was in a long-term relationship at the time of her accident, this failed in a few months as a direct result of her disability:

I had a boyfriend when I broke my neck. It was pretty serious, we'd been together for about two years…that relationship didn't last, it didn't survive the injury really…he was very open about it, and said that over that six months his mates were like "if you stay with her, you're throwing your life away, you're young, you need to cut your losses"…and when he came back he was a different person…he was scared of seeing me…I hadn't had a chance to prove them all wrong, he just listened to everybody else…I felt he was taken from me while I was disabled…I was still weak, I was still at their mercy, I was still being dictated to.

However, even following this heartbreak, Amanda attempted to get back into the dating scene following her accident, for various reasons:

It's different with women as well with sex. Nobody wants to talk about sex or anything, but I do this lecture for midwives about birth and all that…I'm numb from the chest down, and sensation-wise I can feel very little surface sensation, but I do feel deep sensation. I can feel movement, so sex was still a pleasurable activity. I could still have sexual feelings and take part you know…I couldn't swing from the lampshades or anything…

Nevertheless, her only relationship following her accident has since scared her away from any future relationships:

I think that's what went wrong with the relationship I had. I think now, that he was attracted to me because I was in a wheelchair and appeared vulnerable. I think that was the big attraction to him and I didn't see that at all. So I was vulnerable, but not in the way that he thought. And that's actually scared me off a lot of relationships because I don't feel any different at all. But because of the way other people view me…I'm sure I got into the relationship because of the downtrodden way that I'd been rehabilitated…at first it was great and all that, but it actually ended up quite abusive. He was quite a nasty and controlling person, and I remember thinking "if you weren't paralysed you wouldn't be in this situation". And then I felt "so why are you in this situation, because you're not different". I remember actually making the decision and I chucked him out…I had such a bad time with David, who was Michael's dad, that I've never had another relationship again…it's just a conscious decision to look after Michael and not subject him to any danger of that happening ever again. I'm aware that it's not completely healthy, but I don't think it's because of the paralysis or spinal cord injury at all, I think it's because of a totally separate experience I had.

While even able-bodied women run the risk of becoming involved in abusive relationships, disabled women appear to be at an even higher risk, due to their seeming vulnerability. Amanda again commented on her vulnerability when she received hate mail during her pregnancy:

It made me feel vulnerable that people were out there thinking that. Before, I was very self-confident, and now I keep the doors locked, you know, so that people can't walk in unless I want them to walk in. So from that respect

I feel vulnerable, but probably not the vulnerable that everybody else sees me as, if that makes sense

Rachel also commented on her vulnerability:

I do feel more vulnerable, obviously. I kind of think, if anything happens, I can't just get up or, you know, escape from the situation

Due to the extra vulnerability felt by disabled women, trust appears to be an important aspect of a successful relationship – both trust in yourself and your partner. Karen explained:

I remember it taking a long time for me to trust myself with Aaron…it did take a long time for me to really, I suppose, fall hook, line, and sinker, and think "well, this could work". But then you also think, "I'm 21, 22, I've got to start trusting myself or I'm going to be an old spinster on my own". You know, if it doesn't work, it's not going to work, but that could happen to me whether I was able-bodied or not.I could end up going through ten relationships before I find the one I want to finally settle down with. That didn't necessarily mean that just because I was in a wheelchair, that was the way it was going to be…I know I'm incredibly lucky, for him to be the first man I met after my accident, and still be with him now.

In fact, for Karen, many of the issues in her relationship were due to outside influences from her family:

Our relationship was alright, it was just everybody else around us that used to put an awful lot of pressure on. Made me very cross and very bitter towards my parents, although I could never thank them enough for what they did at the start, but they never made my life very easy with him. I know it's probably the old 'father protecting daughter' syndrome, but there comes a point where you have to let go a little bit…They were absolutely petrified I was going to get hurt…but they also didn't understand the fact that I've got to live my life normally, or as normal as possible…There's many a normal relationship that doesn't last long, so you know, after nineteen years, you think, "can he not be happy for me?"… I can understand his concerns at the beginning, you know, "this is just a novelty, she's got some money", you know, I can understand all that, but after nineteen years, if it doesn't work now, it's not for the want of trying...One thing that was never argued about is the accident, the wheelchair, anything related like that. It's always been my parents.

Beyond the trials and tribulations revolving around attempting to form intimate relationships as disabled women, both Karen and Amanda went further and had children following their accidents. According to Thomas (1997), the experiences of disabled women "have been largely overlooked in sociological studies of pregnancy, childbirth and early motherhood…the voices of disabled

women are almost totally absent in sociological work on reproduction and parenting" (p. 623). Grue & Lærum (2002) further explain:

> Disabled women are often looked upon as passive receivers of help and social services, and not as women themselves capable of caring. Within a medical discourse of disability they are mainly perceived as patients and not as women capable of giving birth…disabled women are not expected to be mothers (p. 673)

While both Karen and Amanda have had children following their accidents, in most ways they had very different experiences related to pregnancy and motherhood. However, both commented on the negative reactions they received from family members. Amanda stated:

> When I told my brother, who's a father of three, that I was pregnant he said, "How?" and I said, "you don't know? There's only one way!" And certainly, when they realise I had a child after the accident, the first thing that comes to mind is "how did you have sex"? Sometimes I get fed up of answering the same questions and I'm tempted to say "well we go to a lab…" you know!

Karen reflected on her father's reaction to the news of her pregnancy:

> When I told my dad I was pregnant, he wasn't over the moon, he was so worried about what the consequences could be for me. But I've got to give it a go, I couldn't not, it was the next normal stage in my life

Nevertheless, following the initial hesitant reactions, Karen found a generally positive reaction to her pregnancy and motherhood:

> I was petrified – I didn't know how I was going to cope with a baby…but I knew I'd got a good back up team, Aaron was brilliant…It's just amazing what you learn to do…it wasn't long before I was looking after him for eight, nine hours on my own, and it wasn't a problem…I've never been a "mother's mother"…I'm not a coffee morning type of person…I must admit, all the way through, doesn't matter who I deal with, they've always been very helpful, even at school…obviously I'm not going to be in school everyday like a lot of mothers, so if there's a problem, contact me! I don't want a problem to get out of hand

Conversely, the negative reaction Amanda experienced from certain medical and social care professionals lasted throughout her pregnancy:

> I told my GP I was pregnant and a social worker said to my GP "advise her to have a termination, because as a disabled single mum, she won't be allowed to keep the baby". Three years after my accident, I had my son, Michael, and rather than support me, Social Services took me to court and was going to take my child into care at birth, because they said I was too disabled to look after him…the fight finished four days before I had him – I was under an awful lot of stress right the way through the pregnancy…It was terrible, I went to a pregnancy fair…I was about five months pregnant

and I was going around in a wheelchair, obviously pregnant, and the way I was treated made me feel like a freak. Like an abomination…These reps at the stalls would absolutely leap on any pregnant woman that walked past and give them a leaflet, whereas as I went past, they would not get eye contact and tidy their leaflets or turn their backs on me. And again it's back to this thing that they didn't know how to react, but what was I going to do? I wasn't going to ask them anything about my disability; I was just going to ask them the same questions that any other woman would ask. But I felt stared at…I got a lot of very supportive letters when I was pregnant, but I also got some hideous ones…saying "you filthy pig, what right have you got to have sex?" and stuff like that…I don't think anybody other than Jen, my friend, actually perceived it as something positive…Everybody saw it as "oh no, how am I going to cope with this?". Social Services certainly saw it as "oh this is going to cost millions"…Everybody dealt with it as "oh, it's a problem" apart from one person, who was my closest friend.

Indeed, apart from her closest friends, this negative reaction continued for Amanda through motherhood:

At first, at Michael's school, people didn't speak to me, and they were avoiding me because they didn't know what to say to me. So the kids sort of avoided me too, and then eventually the kids just got used to me being "Michael's mum" and I'll go to parents evening and I'm present at things, so they get used to me being in a wheelchair and now they will actually come up and ride on the back, drive it around, sit on my lap. It's the parents that feel awkward, and not the kids…It's like, I'll go down to collect Michael from school and it's like "oh she's come down in her wheelchair to collect"…but there's nothing you can do about it, apart from ignore it and joke about it.

However, even with the negative reactions she's had to deal with over the years, Amanda loves being a mother:

We've travelled all over the world, and obviously, wherever I go, Michael comes with me…He always comes out at the end of the [cycle] challenges, so he's there when I finish and then we always have a week's holiday in whatever country. So he's walked on coral reefs and picked up starfish…Wrestling's quite an important part of our life at the moment, I have to wrestle daily…cause you know, Michael doesn't give me any consideration for being paralysed, you know I just have to do everything the same as everybody else. So yeah, I have to wrestle and all sorts.

In contrast, the Michelle and Rachel both felt they had never felt a strong desire to have children, even prior to their accidents. Following their injuries, both women commented on not wanting to put children through the difficulty of having a disabled mother. Rachel explained:

It might sound like I've never wanted children, you know? My friends have got kids and that, I'm godmother to them, that's fine for me, do you know what I mean? I don't feel like "oh, it's horrible, I can't have children", it's just something I don't think I'd want. I think also, from the point of view of the

children, I just don't think it's fair to them…I think they should have a childhood, and no matter what you say to them or whatever, I think they always would feel obliged to look after you in a way, and I'd hate that for a child.

Likewise, Michelle commented:

I don't want to be a half mother, like some of them are. I'd always feel guilty that I wasn't doing enough, or somebody else was having to do everything I should have done…I haven't got hands, I can't pick the baby up, or feed it, or do nappies, or when it's toddling, grab hold of it. I can for a small time, but not 24/7. So no, I'd rather enjoy my friends and their children.

Overall, the exceptionally varied experiences of these women in terms of relationships and motherhood aid us in understanding the many difficulties faced by women with disabilities. Indeed, many of the topics covered in this thesis are inexorably tied together; for example, body image inevitably has an effect on one's willingness and ability to take part in intimate relationships. These associations and others will be examined in the following chapter.

4.7 Summary

Each of the topics discussed in this section affects each other in a number of ways. As we have seen, a person's level of comfort with their changed body can affect their perspective on dependence and independence. Similarly, the narrative each woman tells is influenced by the way they experience and view their body. Even their views on the possibility of relationships and motherhood following their accident are shaped by, not only their experience of their bodies, but also the narratives they tell and the identities they create for themselves.

Exactly how each of these areas interact and influence each other is not fully known; however, the four women in this study have deepened our insight into this process. Indeed, the discovery of a new narrative, the resilience narrative, will hopefully have some impact on how we understand disabled women, and how their experience of disability differs from men's experiences.

CHAPTER 5: DISCUSSION

5.1 Implications

At this point, the question I am thinking is: "so what? Why might this research be considered of value?". The answer that comes to mind is "a lot!" Indeed, this research, I feel, has a number of interesting implications and differences from previous similar research on disability.

5.1.1 Gender

Perhaps most importantly, this research has demonstrated that there is a significant difference in the experience of active women who have become disabled through sport, than the experience of active men who have become disabled through sport. For example, in their research on men and spinal cord injury, Smith and Sparkes (2002; 2004; 2005b; 2007; Sparkes & Smith, 2002, 2003) argued that many men faced with major disruptive life events are framed by their relationships towards, and investments in, a disciplined and dominating body. These bodies have elective affinities for certain kinds of narrative. In contrast, the women in this study showed little affinity for the disciplined or dominating bodies and thus, little attraction towards the kinds of narrative these bodies usually tell. Instead, this study suggests that the women interviewed, even though they were highly active prior to their injuries, to have more of an investment in mirroring and communicative bodies. This indicates that the disciplined and dominating body types may have more connection to gender than activity levels prior to injury. Nevertheless, even within the ideal body types the women continued to demonstrate their difference. Frank (1995) believed that the communicative body is told in quest stories, but although all four women in this study displayed a communicative body, only Amanda showed a (weak) affinity for the quest narrative. Thus, both in the ideal bodies they exhibit and the narratives associated with these bodies, the women in this study differ from the men in previous studies.

Indeed, the narratives the women told differed significantly from the narratives told by the men interviewed by Smith and Sparkes (2002; 2004; 2005b; 2007; Sparkes & Smith, 2002, 2003). In their interviews, the vast majority of men

followed the restitution narrative, with a smaller contingent telling a quest narrative and only one speaking in the anti-narrative of chaos. In comparison, this study found none of the women telling a restitution narrative; although they were aware of the restitution narrative, none chose to take this narrative on board as a key way to shape their experiences. In fact, only Amanda showed even a vague affinity for any of the narratives described by Frank (1995), in her weak quest story. The other three women in this study all demonstrated a different narrative, a narrative not yet documented in the literature, which I have called the resilience narrative. This narrative defines itself as a story in which the person "bounces back" from SCI, quietly adapts to a new body, and is malleable in terms of what types of self they perform. It is a plot in which people claim to continue on with their lives with a minimal amount of change.

5.1.2 Identity and Dependence / Independence

This research also demonstrates a link between identity levels, views on relationships and perception of dependence / independence. Both Amanda and Karen demonstrated higher identity levels on the modified hierarchy, and these were also the two women in the study who had a view of dependence that stretched beyond simple physical dependence. In addition, both Amanda and Karen have had relationships and children since becoming disabled. In contrast, Michelle and Rachel have both slipped down the identity hierarchy until they reached the lowest level: the salvaged self. These two women both view dependence in a purely physical manner, and are unhappy with relying on others more than they already do. Furthermore, both Michelle and Rachel have no interest in forming intimate personal relationships or having children, feeling that they would not want to burden another person with their dependency. This apparent link between identity level, relationship views and perceptions of dependence allows us to see how interconnected these various topics are.

5.2 Practical Implications

Having commented on the theoretical implications, we are left wondering about the practical implications of this study. How may we use what we have found

in the real world to improve the lives of women who have suffered traumatic spinal cord injuries?

5.2.1 Alternative Narrative Resources

One major practical implication of this study is the use of alternative narrative resources. In previous studies on disabled men, we have seen problems arise when people become fixated on one type of body and find it hard to remind themselves that other body-self narratives might have to be found and told (Sparkes & Smith, 2002). In this study, however, we have seen four women move away from the popular narratives used by many disabled people in society, and draw on another narrative to fit their experiences into: the resilience narrative. This is very important, because this counter-narrative has the potential to add to the therapeutic and transformative possibilities of the collective story, as described by Richardson (1990), that challenges the mainstream stories that people attempt to fit their lives into:

> Collective stories that deviate from standard cultural plots provide new narratives; hearing them legitimizes replotting one's own life…By emotionally binding together people who have the same experiences, whether in touch with each other or not, the collective story overcomes some of the isolation and alienation of contemporary life…It provides…the linking of separate individuals into a shared consciousness. Once linked, the possibility for social action on behalf of the collective is present, and, therewith, the possibility of societal transformation (Richardson, 1990, p. 26)

These collective counter-narratives are immensely important, as Thomas (1999) comments:

> Without the counter-narratives of others who challenge social "norms" we, as isolated individuals, are trapped within the storylines of the prevailing narratives. If we do re-write our own identities then we strengthen the counter-narrative, and the dominant and oppressive social narratives begin to crumble (p. 55)

However, it should be noted that while the resilience narrative is certainly one that hasn't been documented in the literature to date, it does not fully challenge social "norms". While it is a different narrative from the commonly used restitution narrative, which society approves of, it is still one which involves little social action or call for change. It is simply one which accepts the different paths might take us

down, and "moves on". Nevertheless, it still gives disabled women the ability to access a different kind of collective story with which to re-plot their lives

5.2.2 Body Image

As we have seen in the previous chapter, body image came across as an important aspect in these women's lives. This may be tied to the participants' affinities for the mirroring body, which attempts to recreate the body in the image of other bodies. Indeed, the mirroring body's fear of disfigurement played a role in the psycho-emotional well being of all the women in this study. Indeed, the women in this study, overall, seem to be locked into the typical "feminine ideals" about body image that perpetuate social "norms". One practical implication that may be taken from this study would be the use of techniques in order to improve the body image of disabled women; however, care needs to be taken when undertaking such techniques, because it washes out the effect that society itself has in creating these negative body images. As such, another strategy could be to challenge societal views of the "normative" body. One way to do this may be to give women access to different stories of being a woman who is also disabled – another collective story.

5.3 Contributions to the Field of Study

This work makes a number of contributions to various fields of study: the sociology of the body; feminism; medical sociology; and disability studies.

This work contributes to the sociology of the body in the following ways. It highlights how the body is a real, material entity that is shaped by narratives out there in society. Equally, it reminds us that people can resist and edit these narratives, thereby highlighting the agency of the body. In addition, it demonstrates that the body is both a social construction and a biological reality.

This work contributes to feminism by showing that disability studies does have many contributions to make in relation to this field. As mentioned in Chapter 2, disabled women have been caught between the field of disability studies, in which they have been invisible as women, and feminism, where their disability has been ignored or subsumed (Lloyd, 2001). This study has attempted to view the

participants' lives from both disabled and feminist perspectives, and has allowed us to delve deeper into the reproductive rights of disabled women.

This work contributes to medical sociology by bringing the notion of resilience to the table. In addition, it questions the pendular model of identity reconstruction proposed by Yoshida (1993), and adds new layers to the identity hierarchy proposed by Charmaz (1987).

Finally, this work contributes to disability studies in the following ways. It helps to stress the importance of independence of thought and action, as opposed to physical independence in relation to self-care activities. In addition, it shows us that the psycho-emotional dimensions of disability may be an especially important aspect to focus on in relation to disabled women. All of the women in this study displayed aspects of the mirroring body-self, which fears disfigurement; therefore, psycho-emotional disability may have more significant effects on disabled women than disabled men.

5.4 Limitations and Future Directions

This study, like any study, had its fair share of limitations. The biggest limitation for this study was the small sample size. While this was the best sample size I could attain given the time constraints and lack of participant response, it would have been interesting to see if the results found in this study are widespread among women with disabilities, or only an occurrence in this sample. Future studies could look into researching more women disabled through sport, and also including women disabled via other means. In this manner, they could uncover whether the differences we have found are due to gender differences, or the manner of the injury.

In addition, due to time constraints and scheduling difficulties, each participant was only interviewed once, with follow-up questions answered via multiple telephone calls and e-mail contact. While each of these interviews was in depth and uncovered many interesting topics, and both these techniques for data collection are increasingly being used and legitimised, further interviews to expand upon particularly interesting areas may have been useful. Future research could

focus on following participants' stories over an extended period of time and attempting to observe identity level shifts as they occur.

5.5 Conclusions

This research has presented data from four women's accounts of their life stories to date. This research has been very important because it demonstrates how differently women respond to a traumatic spinal cord injury via sport. It has illuminated some possible connections between topics often viewed as separate. In addition, it has illuminated the emergence of a new narrative, the resilience narrative. The findings in this study are far from definitive; rather, they reveal some exciting possibilities. Therefore the findings need to be treated with caution, for many other questions yet remain. My hope is that this research encourages others to research issues surrounding women, SCI and sport.

APPENDIX 1
Spinal Injury Chart
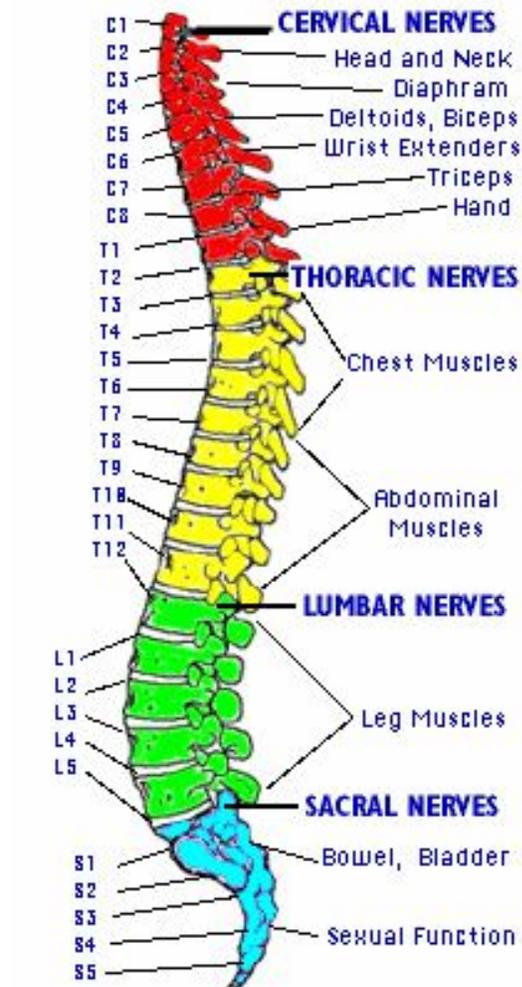
Level of Injury	Motor Abilities
C1-C3	Limited movement of head and neck
C3-C4	Usually has head and neck control. Individuals at C4 level may shrug their shoulders
C5	Typically has head and neck control, can shrug shoulder and has shoulder control. Can bend elbows and turn palms face up.
C6	Has movement in head, neck, shoulders, arms and wrists. Can shrug shoulders, bend elbows, turn palms up and down and extend wrists.
C7	Has similar movement as an individual with C6 with added ability to straighten elbows.
C8-T1	Has added strength and coordination of fingers with limited or even normal hand function.
T2-T6	Has normal motor function in head, neck, shoulders, arms, hands and fingers. Has increased use of rib and chest muscles and may have some trunk control.

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