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Negotiation of disability and impairment within counselling relationships: a critical evaluation from the perspective of clients with spinal cord injuries

By

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Submitted for the Degree of Master of Arts in Disability Studies, September 2000

Abstract

This empirical study explores the counselling experiences of clients with spinal cord injury (SCI) with particular reference to the ways in which issues about disability and impairment were discussed by both counsellor and client. The effects of the counsellor's understanding of disability and impairment on the counselling outcome are also considered together with factors that would improve the quality of counselling for future clients. It builds on a study carried out five years ago which considered the counselling experiences of disabled clients from the perspective of the counsellor; one of the acknowledged omissions from this study was the voice of the disabled client. This research also draws on recent discussions within disability studies about the psycho-emotional dimensions of disability and the complex ways in which the experience of living with disability is intertwined with the experience of living with impairment.

Five participants were involved in the research who all had experience of counselling with one or more different counsellors or psychologists since injury. The research was carried out within the emancipatory research paradigm using qualitative methods. Interviews took place with each participant in which they discussed the ways that disability and impairment issues had been handled within past counselling relationships.

The ways in which these participants described their experiences of disability and impairment were rich and complex and revealed an interdependence not explained by a simple social/biological dualism separating disability from impairment. Participants discussed the emotional effects of incontinence highlighting an aspect of the 'personal' experience of impairment that has been neglected within the literature. The structural and emotional effects of disability were also discussed with counsellors and it was found that counsellors who did not understand disability as a social construct, failed to counsel effectively and often further oppressed their disabled clients. Participants also found it helpful if the counsellor themselves had knowledge of SCI and was able to pass on information and advice.

These observations have many implications for counselling practice. I suggest that counsellors working with disabled people need to work within the framework of the social model of disability to avoid further disabling their clients. I propose that in addition to making Disability Equality Training (DET) a mandatory part of all counselling courses, this DET must include reference to the psycho-emotional dimension of disability and the ways in which disabled people internalise the negative prejudices and attitudes held by the society they live in. I also argue that a new counselling approach might be more suitable for disabled people which recognises the multiple effects of disablism and offers a more directive counselling approach to empower disabled clients.

I evaluate my research practice and identify the lessons I have learnt from this research experience. Finally I discuss these problems in the light of recent attempts at participatory research within counselling research and propose that emancipatory research offers a new methodology for counselling research which is highly suitable for researching the counselling experiences of oppressed groups in society – areas which are absent within counselling research to date.

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Acknowledgements

This dissertation is the culmination of nine months gestation and I would like to thank all the people who have contributed to my project.

Chapter 1

Introduction

At the same time as disabled people have been working towards collective empowerment, they have also been voicing a demand for more counselling that meets their individual needs (Lenny, 1993). Studies looking at the experiences of men and women living with spinal cord injury (Oliver et al., 1988; Morris, 1989) have shown that many people felt that they would have benefited from having access to counselling during hospitalisation and following discharge. This demand for counselling is also considered by Derbyshire Centre for Integrated Living (CIL) to be one of the seven core areas of support for disabled people wishing to live independently in their communities (Priestley, 1999). There are many different types of counselling which disabled people might have access to, offered by a variety of organisations and individuals; for example many CILs and user led organisations offer peer counselling although this service can range from a service which uses disabled people to counsel other disabled people, to an advice and information giving service (Evans, 1993).

The British Association for Counselling (BAC), which is the largest counselling organisation in the UK, describes counselling as:

> '… an opportunity for the client to work towards living in a way he or she experiences as more satisfying and resourceful … the counsellor's role is to facilitate the client's work in ways which respect the client's values, personal resources and capacity for choice within his or her cultural context … [and] involves a deliberately undertaken contract with clearly agreed boundaries and commitment to privacy and confidentiality' (BAC, 1996a; 1).

The term 'client' is used here to describe any person who engages in counselling with a counsellor. Counselling can be described as a 'helping' relationship characterised by certain 'core conditions' offered by the counsellor - empathic understanding, unconditional acceptance and genuineness (Nelson-Jones, 1982). In counselling these conditions are considered to be the essential minimum for a working alliance between counsellor and client, irrespective of the theoretical orientation of the counsellor. Counselling places a strong emphasis on helping someone develop their own sense of empowerment and is not usually about giving advice or information to people (McLeod, 1998). I will be using these definitions of counselling for this research project.

I became interested in the counselling experiences of disabled people when I trained as a counsellor myself at the same time as identifying as a disabled person. Counsellors who adhere to the BAC code of practice are expected to remember that they have:

> '… a responsibility to consider and address their own prejudices and stereotyping attitudes and behaviour and particularly to consider ways in which these may be affecting the counselling relationship and influencing their responses' (BAC, 1996a; 1).

As the BAC does not require Disability Equality Training (DET) to be taught on their accredited counselling courses (BAC, 1996b), it would seem unlikely that counsellors would always recognise their own disablist prejudices and attitudes or understand the effects that disadvantage, discrimination and disablism within society has on disabled people (Reeve, 2000).

This problem is compounded by popular counselling theories which describe how a person 'copes' with disability. As I will show in Chapter Two these 'loss' theories, only provide a model for how some people might respond to losses associated with impairment and do not begin to address how people respond to disability. In presenting disability as a loss that *must* be grieved and adjusted to, these theories reinforce negative stereotypes of disabled people as bitter and self-pitying – such people are viewed as not having 'accepted' their disability (Oliver, 1990). Most of the counselling literature is written within this medical model view of disability which identifies disability as an individual tragedy. However, for most disabled people, the real problems come from living in a disabling environment rather than from the experience of impairment (Oliver, 1995). This observation supports the social model of

disability in which disability is caused by 'externally imposed disadvantage and social restriction' (Oliver and Barnes, 1998; 18) rather than impairment.

In my own counselling I continually have to educate my counsellor about what it means to live in society as a disabled person. My relationship with the social model of disability has given me insight into why I find it difficult to be 'heard' – my counsellor and I have different perspectives on what disability and impairment mean for a disabled person. These experiences have led me to consider how helpful counselling is for disabled people given that counsellors are often at best ignorant of what disability is, or at worst can repeat the oppression experienced by disabled people in society within the counselling room itself.

Oliver (1995) studied the experience of counselling disabled people from the perspective of the counsellor and concluded that counselling should aim to enable disabled people to empower themselves. One of the most effective ways of achieving this is by helping disabled people to see that many of the difficulties they experience are not individual failures to 'cope' with their disability, but instead are restrictions caused by a society which fails to take their impairment into account. It was also acknowledged that a glaring omission from this study was the voice of the disabled client. The voices of disabled people have also been absent in counselling research to date (McLeod, 1994). This study will attempt to redress the balance by considering the experience of counselling from the perspective of clients with spinal cord injuries (SCI). Drawing on the link between a social model view of disability and client empowerment I will focus on how the issues of impairment and disability are negotiated between counsellor and client and how this affects the counselling experience. I will also consider how the client's own attitudes towards impairment and disability affect and are affected by those of the counsellor over the duration of the counselling relationship. The results of this research will, I hope, be used to inform future counselling research, training and practice.

These ideas have led me to propose the following research questions which will underpin this piece of research:
• How are the definitions of impairment and disability understood and negotiated by the counsellor and client throughout the duration of the counselling relationship?
• What effect do these definitions have on the way in which issues brought to counselling are worked with?
• In what ways do people with SCI find counselling helpful or unhelpful for dealing with disability and impairment related issues?
• What additional training or experience do counsellors need in order to improve the counselling experience for people with SCI?
• How relevant is the emancipatory research paradigm for counselling research?

I will be considering two elements of disability as defined by Thomas (1999a) who suggests that in addition to the social barriers that are experienced as externally imposed 'restrictions on activity', there are also social barriers that place limits on the psycho-emotional well-being of a disabled person and which are continually reinforced by the society we live in. One example of this psycho-emotional element of disability would be internalised oppression that prevents disabled people 'being' who they want to be. I will be looking to see how both the structural and psycho-emotional aspects of disability are revealed and managed by the counsellor and disabled client within counselling. Additionally I will consider the ways in which the disabled client discusses the physical and emotional effects of impairment with their counsellor.

This research spans the academic disciplines of both disability studies and counselling; in Chapter Two I discuss some of the criticisms of counselling which have been made by disabled people and consider the ways in which current counselling practice can further oppress disabled clients. I also describe in more detail the ways in which disability and impairment can affect the emotional well-being of disabled people including a discussion of the phenomenon of 'internalised oppression'. Finally I will show that counselling research has neglected the counselling experiences of disabled people and place the methodology used in this piece of research in context with the current discussions about the use of new 'qualitative' methodologies within counselling research. A detailed description of my research methods

used to carry out this attempt at emancipatory research are described in Chapter Three, together with a discussion of the problems I encountered generating my data.

Chapter Four focuses on the main issues about impairment and disability which were described by my participants. Each account is analysed to identify the different dimensions of disability and impairment present and I reveal the complex ways in which these dimensions are intertwined. I also expose the ways in which the attitudes and prejudices of some counsellors further disabled their clients with SCI. The aspects of counselling which are helpful and unhelpful to this client group are then discussed further in Chapter Five. I describe the factors which clients with SCI might find helpful in counselling and suggest that the counselling needs of this group, and maybe other disabled people, might be better served by a different counselling approach to that of non-disabled people. I also highlight areas of practice which need improving to make counselling accessible for disabled people and propose that the DET provided for counsellors on training courses needs to include reference to both the structural and psycho-emotional aspects of disability in order that counsellors can understand the internal world of their disabled client. In Chapter Six I evaluate the extent to which this research was truly emancipatory and discuss some of the personal lessons I have taken from this research experience. I then draw on these personal reflections to consider how applicable emancipatory research is for counselling research and suggest areas which need further consideration if this new paradigm is to be applied. Finally in Chapter Seven I summarise the findings of this research and make my recommendations for further research and discussion.

Chapter 2

Counselling and Disabled People

This research bridges the academic worlds of counselling and disability. Counselling has been criticised within disability studies for failing to meet the needs of disabled people, both in terms of counselling theory and practice. I will describe some of these criticisms and indicate the ways in which counselling fails to address disability as a social construction. The emotional effects of disability and impairment are then described, issues which are currently under-theorised in disability studies. Finally I will consider the current state of counselling research on the experiences of disabled clients and briefly discuss the current trend towards using new methodologies within counselling research.

The 'loss' theories

The most common psychological theories designed to explain personal responses to disability are based on the assumption that there will be psychological *adjustment* as the individual comes to term with their impairment. The idea of needing to 'psychologically adjust' to disability has been added to by various grief and stage theories to generate yet more theories about how people respond to disability (Oliver, 1995). These theories predict that disabled people are expected to grieve, mourn and express feelings of anger and denial, before they can become psychologically whole again (Webb, 1992). This concept of how disabled people must grieve their losses to become 'whole' again not only applies to people who acquire impairments; people with congenital impairments are also assumed to experience loss when they realise how they differ from what is regarded as 'normal' (Webb, 1992).

There have been many criticisms of these 'loss' theories. The suggestion that disabled people *need* to adjust to this change leads to the assumption that becoming disabled is psychologically devastating and that such a personal tragedy can only be resolved by grieving the loss (French, 1994a). Therefore this 'loss' theory arises from the medical model of disability in which impairment is seen as the cause of disability and posits disability as an individual tragedy (Bury, 1997). The idea of 'adjustment' implies a judgement of what is 'normal' and what is not. As a result, loss may be 'found' in many aspects of a disabled person's life – loss of functional capability, body-image, sexuality, social roles, employment, familial role etc. (Lenny, 1993).

These 'loss' theories have been heavily criticised by disabled theorists for not taking into account the social dimension of disability (Oliver and Sapey, 1999). When a person acquires an impairment or becomes chronically ill then their lives *will* be changed in some way, but these 'loss' theories assume that the only reaction will be one of personal loss and overlook all the other reactions which a person might have. Some people may find that the experience of impairment causes feelings of loss about e.g. bodily function or future life choices; a bereavement or 'loss' theory might be appropriate in this case. However for most disabled people it is the experience of disabling physical and social barriers, rather than living with impairment that causes difficulties (Oliver, 1995). Therefore the 'loss' theories which claim to explain personal responses to disability are only considering *possible* personal responses to *impairment* and ignore the emotional distress experienced by disabled people living within a disabling environment. It has been shown that there is limited evidence for the validity of these stage models (Robertson, 1992; Trieschmann, 1988), and yet they are still often presented as the only way that people respond to disability (McKenzie, 1992). There is empirical evidence that becoming disabled is not necessarily associated with loss, and for some people life is *improved* after they became disabled (Morris, 1989; Kennedy, 1998). There is also no allowance within these 'loss' theories for the fact that people are unique and will respond differently depending on age, life experience, social resources, personality, financial situation etc. (Borsay, 1997; Trieschmann, 1988).

Disability within counselling literature

The counselling literature generally presents disability as a problem for the individual (e.g. Brearley and Birchley, 1994; Godden, 1996), advocates the use of the 'loss' models to predict how people respond to disability and fails to consider disability as a social construct. Segal has written chapters in several counselling text books (Segal, 1989; 1995; 1997) and considers that:

> 'Counselling disabled people may, like nursing, be considered a worthy thing to do because it implies we have in some sense overcome a natural revulsion' (Segal, 1995; 59),

before proceeding to acknowledge that prejudices about disability can affect the beliefs of the counsellor! There are two notable exceptions to this 'medicalisation' of disability in the counselling literature - significantly both authors are disabled counsellors. Corker (1995) addresses the issues of power and oppression within the counselling relationship when a counsellor is working with a deaf client. Olkin (1999) writes from a US perspective and devotes half her book to describing the different models of disability and the ways in which disabled people are excluded and denigrated by society before discussing the issues which disabled people might bring to counselling such as the experience of discrimination and disablism. Unfortunately it is the former type of text books which appear on the reading lists for counselling training courses from which counsellors will learn about disability, with the result that counsellors will understand disability as an individual problem rather than as a social construction.

Availability of counselling

Despite the assumption that people with acquired and congenital impairments will need to mourn their 'losses', it is notable that there are far fewer counselling services available to people with congenital impairments. This could be due to several mistaken assumptions about people who are born with an impairment. One assumption is that people with congenital impairments are not exposed to 'biographical disruption' (Bury, 1997) in the same way as people who become disabled in later life and therefore do not need counselling. Another myth proposed by French (1994b) is that people with congenital impairments 'don't know what they are missing' and have developed qualities and attributes to compensate - however people with acquired and congenital impairments are all disabled by society. Therefore it is reasonable to assume that both groups of disabled people might want access to counselling. Disabled people may want counselling to help resolve issues resulting from dealing with the medical profession (Oliver, 1995), living with pain and exhaustion (Crow, 1996), the experience of internalised oppression (Keith, 1996), as well as the experience of living in a disabling society. This is in addition to the problems which disabled people, like the rest of society, may take to counselling such as bereavement or relationship difficulties (Withers, 1996).

Lack of accessibility in the built environment generally, together with the fact that disabled people are a financially disadvantaged group within society (Barnes, 1991) means that counselling is not accessible to many disabled people. Oliver (1995) concluded that counsellors needed to be more flexible in undertaking home visits to compensate for inaccessible counselling premises; this is only one of many ways that counselling agencies will need to change now that Part Three of the Disability Discrimination Act regarding access to services has come into effect (Reeve, 2000). Disabled people also have little choice about whether or not they see a disabled or non-disabled counsellor because there are very few disabled people going through training to become counsellors (Withers, 1996). There is still some debate about whether disabled counsellors can counsel other disabled people (Oliver, 1995); whilst disabled counsellors may have a 'shared' experience of disability, their own subjective experience of disability and unresolved issues might prevent them from working effectively with disabled clients. The issue about whether or not counsellors should be disabled themselves will be explored in this research and discussed in Chapter Five.

The access to counselling for people with SCI is improving. Oliver et al. (1988) showed that whilst the medical and physical rehabilitation was of a high quality, there was little attention paid to the emotional needs of people with SCI. Morris (1989) describes how SIUs expected

people to maintain a 'stiff upper lip' and there was not space for people to break down and cry. Today, Stoke Mandeville has clinical psychologists and peer counsellors working within the SIU although it is not clear who gains access to these services as most SIUs only refer the 'most disturbed' for assessment and counselling (Kennedy, 1991).

Counselling approaches

Criticisms have also been made of the different counselling approaches used by counsellors (Lenny, 1993). The three most common approaches are psychodynamic (insight orientated), cognitive-behavioural (goal orientated) and humanistic (facilitative) (Miller, 1997). Psychodynamic counselling works with the conscious and unconscious and considers disability to be an assault on the ego (Lenny, 1993). Apart from the fact there is little evidence to support this suggestion, Lenny (1993) doubts that psychodynamic theories can provide a full basis for understanding the experience of disability. Cognitive-behavioural counselling is concerned with developing skills and techniques to allow people to control interpersonal, emotional and decision problems by altering their behaviour (Nelson-Jones, 1982). Lenny (1993) rejects this counselling approach because it fails to account for the fact that disabled people are unable to take control of their lives because of a disabling society, and not because disabled people are helpless. French (1994c) believes that cognitive-behavioural approaches do have some uses, especially in challenging negative thinking patterns and enabling people to increase their sense of self-worth and self-confidence. This is reflected within the SIU community where cognitive-behavioural approaches are considered to be the most effective way of helping improve the self-efficacy and coping style of someone with SCI (Kennedy, 1998).

Within humanistic counselling the counsellor believes in the inherent goodness and self-worth of the client and holds that each client has the ability to reach their full potential (Woolfe, 1996). The client is the 'expert', with the counsellor being present to facilitate the personal work of the client towards self-control, self-help and personal power (Nelson-Jones, 1982). Humanistic counselling is also relatively free from labels and stereotypes and does not make judgements about how people adjust to their disabilities (Lenny, 1993). Whilst humanistic counselling offers a counselling approach which allows for the experience of disability as a social construct, cognitive behavioural counselling has some uses for improving self-efficacy and confidence.

Oliver (1995) concluded that disabled people needed access to the same counselling as non-disabled people – that:

> 'Disabled people's underlying emotional issues were the same as able-bodied people's' (Oliver, 1995; 273).

However I feel that this conclusion is flawed as it ignores the emotional effects of disablism. In the same way that the term 'disabled person' is a better reflection of the meaning of disability than 'person with a disability' (Oliver and Barnes, 1998; 18), I do not consider it helpful to ignore the significance of the experience of disablism, which is an exclusive experience of disabled people. It has been recognised that counsellors working with people of a different culture or ethnic grouping need to be aware of the impact of racism within society and that counselling approaches and techniques need to reflect this issue of difference (Lago and Thompson, 1996). It may be appropriate for a similar counselling approach to be used when working with disabled people which recognises the impact of disablism within society (Reeve, 2000).

There is some debate as to whether counsellors should know about the client's medical condition; some counsellors felt that their relative lack of knowledge empowered the client (Oliver, 1995). However Oliver et al. (1988) criticised health professionals for their lack of knowledge about SCI and Lewis (1999) showed that disabled clients with Multiple Sclerosis (MS) found it helpful if the counsellor had medical knowledge of this condition. Chapter Five will look at the effect that counselling approach and style had on people with SCI in this research.

Oppression in the counselling room?

Counselling is still in the process of changing from an amateur vocation to a profession helped along the way by national accreditation schemes run by organisations such as BAC (Feltham, 1996; Wheeler, 1999). A counsellor could be seen as yet another professional who is trying to 'fix' disability by helping the disabled person change (Davis, 1993; Withers, 1994). Criticisms have been levelled at professionals working with disabled people (Barnes and Fiorentino, 1998) and some of these are particularly relevant to counsellors.

Counselling cannot make a valid claim to political neutrality as counsellors are overwhelmingly white, middle-class, heterosexual, non-disabled people who attract clients with similar social power and status (McLeod, 1998). Counsellors also need to be aware of their lack of expertise in the field of disability. In order to counsel disabled people effectively, health professionals such as psychologists and counsellors need to have a thorough understanding of disability (French, 1994c). However the counselling literature and theory present a medical view of disability, so counsellors are unlikely to see disability in the same light as other issues of 'difference', such as when counselling people from different cultures or sexual orientation.

Finally, a criticism of psychotherapy, and by implication of counselling, is the way in which the client is offered a 'false' friendship which can be destructive for counsellor and client. This corruption of friendship results in private counsellor-client relationships at the expense of friendships within society (McLeod, 1998). Consequently counselling can individualise and pathologise what are in reality conflicts between people and within society, disempowering the client (McLeod, 1998). This is especially true when counselling disabled people because so many of the issues which affect this particular client group are created by society rather than the individual (Ley, 1994).

It could be predicted that because many counsellors are completely unaware of their own disablist prejudices and attitudes, the oppression which disabled people experience within society is often repeated within the counselling relationship (Reeve, 2000). Disability Equality Training as part of training courses which teaches counsellors about the social model of disability would be helpful (Oliver, 1995; Lewis, 1997); this would enable counsellors to empower their disabled clients by reframing individual problems in 'coping' as difficulties caused instead by a disabling environment (Oliver, 1995). However the provision of DET for counsellors may only offer a partial solution and disabled people may be better served by a new counselling approach with the social model at its core or one of the emerging 'anti-oppression' approaches (Reeve, 2000). This research will explore how the attitudes and prejudices held by counsellors about disability and impairment affect the counselling relationship and will be discussed further in Chapters Four and Five.

Definitions of disability and impairment

Since the publication of the article by Oliver (1995) within disability studies five years ago, there has been very little further discussion about counselling and disabled people. I believe that in part this relates to the ongoing heated debates about whether or not the social model of disability acknowledges the role played by impairment and illness in the life experiences of disabled people (Crow, 1996; French, 1993; Morris, 1991); by extension counselling could be considered to be related to the 'personal' issues connected with living with impairment or disability effects. Some disabled feminist writers such as Thomas (1999a) have commented that these 'personal' issues are considered to be outside of the social model perspective that operates at the 'public' level dealing with oppressive social barriers. As a result the social causes of oppression which operate at the emotional level are not being publicly discussed.

Whilst counselling cannot 'fix' socially constructed barriers which affect what disabled people can *do*, it has an important role in understanding and working with the psycho-emotional dimension of disability, social barriers which place limits on the psycho-emotional well-being of a disabled person (Thomas, 1999a). These social barriers include being hurt by the reactions of other people, being made to feel worthless, unattractive and hopeless and originate from the socio-cultural processes which create the negative attitudes and prejudices

about disability and impairment so endemic within our society. The agents of this disablism can be close family members or individuals with whom disabled people have direct contact such as counsellors, in addition to disablism experienced within society at large (Thomas, 1999a).

An important element of this psycho-emotional dimension of disability is 'internalised oppression' which Mason (1992) describes in the following way:
> 'We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives' (Mason, 1992; 27).

Marks (1999a) considers internalised oppression from a psycho-analytic viewpoint and describes it as the 'unconscious defences deployed by disabled people in the face of oppression' (Marks, 1999a; 614) and comments that it is most effective when disabled people are unaware of its existence. The relationship between internalised oppression and what Thomas (1999a) calls the 'psycho-emotional dimension of disability' has not yet been theorised. For the purposes of this research I will consider internalised oppression to be the most important example of this emotional aspect of disability, whilst acknowledging that there may be other examples of the psycho-emotional dimension of disability.

The experience of internalised oppression is described clearly by Rieser (1992) who writes frankly of the ways in which he self-injured when depressed – 'I didn't like myself and I was pretty sure no-one else did either' (Rieser, 1992; 31). Keith (1996) discusses strategies for dealing with internalised oppression and shows how important is it for disabled people to share experiences, to understand the ways in which prejudice and discrimination contribute to this emotional aspect of disablism. Counselling can also help people uncover and resolve internalised oppression, to repair this negative relationship that they have with themselves, although it is vital that these unconscious defences are not stripped away by over-eager counsellors without putting anything positive in their place (Rieser, 1992). In practice, my own experience shows that even counsellors who have an understanding of the social model of disability together with an awareness of the prejudices and stereotypes of disabled people within society, will have no appreciation of how disabled people internalise their oppression – hence it remains hidden and unresolved.

One important element of internalised oppression is a result of the way in which disabled people are not considered as fully sexual beings (Shakespeare et al., 1996; Gillespie-Sells et al., 1998). As a result disabled people can be prevented from having healthy sexual identities and active, life-enhancing sex-lives:
> ' "My impairment itself doesn't restrict my sexual activity, what restricts my sex life now is other people's perceptions about my impairment, very definitely!" ' (Dafydd, in Shakespeare et al., 1996; 41).

Treatment at the hands of the medical profession can also have a negative effect on how a disabled person sees themselves. Evidence has shown that:
> 'The coldness and formality, the lack of privacy, the objectification of the patient, the lack of communication, and the voyeurism constitute a violation, not a legitimate procedure. This state of affairs can undermine a disabled person's feeling of ownership and of the body' (Shakespeare et al.,1996; 142-143).

Low self-esteem about being disabled and unlovable can also lead to a disabled person tolerating abuse in order to get affection (Gillespie-Sells et al., 1998).

In the same way that disability has a psycho-emotional dimension, the experience of impairment effects also has an effect on the emotional well-being of a disabled person (Thomas, 1999a). Despite claims by Crow (1996) that it is taboo to talk about impairment, there are many personal narratives about the effects of living with impairment in the literature e.g. the experience of living with physical impairment (Lonsdale, 1990) and spinal cord injury (Morris, 1989; Oliver et al., 1988). In the latter two studies people described the ways in which the experience of pain, fatigue and incontinence seriously undermined their emotional health. However, discussions about the psycho-emotional dimension of impairment effects in the literature (e.g. Crow, 1996; Finkelstein and French, 1993; Thomas, 1999a) fail to mention the shame and humiliation of incontinence. Incontinence affects more than three million men and

women in the UK and is a highly stigmatising impairment which remains a taboo subject in society (Carter, 1997).

> ' "I think that my bladder is the worst thing, even than being in a wheelchair" '
> (Theresa, in Morris, 1989; 150).

There has been relatively little research into the social aspects of the experience of living with incontinence. A recent study by Cavet (1998) serves to highlight the importance of including humiliation and shame associated with incontinence alongside the other 'less taboo' psycho-emotional dimensions of pain and fatigue. If the 'personal' experience of impairment is to be included within a social theory of disability (Oliver, 1996), then this must include *all* the experiences of impairment, including the 'unspeakable' ones such as incontinence.

Whilst it is possible to analytically break down how disabled people have their emotional well-being affected by disability and impairment, in reality disability and impairment effects are not so easily separated (Thomas, 1999a). Disabled people, like all people, have a multi-faceted identity affected by gender, class, race, sexuality etc. (Shakespeare, 1996).

> 'The 'lived experience' is thus rich and multi-dimensional, where already complex
> features of impairment effects and disability meld together with other facets of our
> social identities' (Thomas, 1999a; 48).

Chapter Four will describe some of the ways in which the intertwined issues of disability and impairment are discussed within counselling relationships.

Disability within counselling research

The tendency of counselling to ignore the social aspects of disability reflects the fact that there is very little counselling literature or research that considers the *social* issues affecting oppressed groups in general (McLeod, 1994; 1998). Counselling research is recognised to be under-developed in the UK and until recently was dominated by studies which measured only the outcomes of counselling, revealing the strong historical link with psychology (McLeod, 1994). This link is seen within the few articles about counselling disabled people which have appeared in the two main British counselling research journals, the *British Journal of Guidance and Counselling* and *Counselling Psychology Quarterly*; the research is generally based in medical settings and ignores the social aspects of disability (e.g. Stewart, 1987; Balmer, 1989; Burton et al., 1992; Griffiths, 1993). Whilst there are an increasing number of studies which attempt to explore the internal processes within the counselling relationship, such as client experience studies (e.g. Brannen and Collard 1982; Maluccio 1979), there are a dearth of studies looking at the experiences of clients from oppressed groups within society.

Lewis (1997) considered the unmet needs of relationship counsellors working with disabled people, and the unmet counselling needs of disabled clients, specifically people with MS and their families. This study addressed questions about how counsellors felt about working with disabled people and finding out what clients with MS wanted from counselling. The findings from talking to clients with MS were that they wanted someone to talk to but did not want to be told what to do. The other conclusion was that counsellors did not need:

> '… disability awareness training for counsellors, but a need to extend the awareness
> training into what constitutes culture' (Lewis, 1997; 8).

The research was based on an understanding of disability being interrelated with illness (medical model approach); however Lewis has still reached the conclusion that counsellors need Disability Equality Training rather then disability awareness training (Withers, 1994). I will compare the results of my research with this small counselling study and the research done by Oliver (1995) described previously.

In recent years research examining the experience of counselling from the perspective of the client has utilised qualitative methods because of the richness of analytical data that is produced. However this methodology is still in the 'trial phase' as far as counselling research is concerned (McLeod, 1994; 1996). Some 'participatory' research has been carried out (e.g. Etherington, 1996; Grafanaki 1996) which attempts to share responsibility with the research participants. Whilst this reflects the future direction of counselling research towards a methodology that better reflects the values of counselling itself – reflexivity and empowerment (McLeod, 1997) – it also causes difficulties and dilemmas for researchers attempting this kind of research, especially the dual relationship of counsellor and researcher (Hart and Crawford-

Wright, 1999). Emancipatory research has not been attempted within counselling research; these lessons of 'participatory' counselling research will be discussed further in Chapter Six when I discuss my own experiences of attempting emancipatory research to explore the counselling experiences of people with SCI.

Summary

There has been very little discussion about the counselling experiences of disabled people within disability studies or the counselling literature. Counselling has been criticised by disability theorists for failing to acknowledge disability as a social construction and as a result further oppressing disabled people. At the same time, the emotional effects of impairment and disability, particularly internalised oppression, have been acknowledged as having a deleterious effect on the well-being of disabled people. This research will contribute to the debate on whether counselling has anything to offer disabled people as well as the ways in which disability and impairment effect the psycho-emotional well-being of disabled people. This research will also address the lack of studies looking at the counselling experiences of oppressed groups in society and will apply a new research methodology which is particularly suitable for the study of oppressed groups in society (Oliver, 1992). The next chapter will look at the methods used in this research study and discuss the problems encountered along the way.

Chapter 3

Research Methods

In this chapter I will describe the methods I used to find my sample, generate and analyse my data. At each stage I will discuss the reasons for the methods used and describe the problems I encountered. Finally I will mention the particular ethical considerations of this research project and discuss the problems I encountered when interviewing one particular couple.

Methodology

My ontological position is heavily influenced by my experiences in counselling as a client, trainee and trained counsellor in addition to my politicisation as a disabled person. Disabled counsellors training on mainstream counselling courses are a rarity because such courses are expensive and often inaccessible (Withers, 1996) and so I occupy a relatively unusual position between counselling and disability theory, one which has felt very lonely at times.

Social research is a political activity because the process and products can never be neutral (Vernon, 1997); as a result it can be used to increase or reduce oppression. My biography is an important part of this research alongside the experiences of my participants and I believe that this can only 'enhance the claim of the work to make morally and politically important statements' (Clough and Barton, 1995; 5). I will therefore be aspiring to work within the emancipatory research paradigm which is:

> '… about the facilitating of a politics of the possible by confronting social oppression at whatever level it occurs' (Oliver, 1992; 110).

This new methodology seeks to change the social and material relations of research production and has three fundamental aims – reciprocity, gain and empowerment. I will discuss my experiences of working within this paradigm in Chapter Six. I will now describe the qualitative research methods and tools which were used during the research process and then discuss the problems which occurred during the data collection phase.

The Sample

I commented in the last chapter that it is people who acquire impairments, such as SCI, who are usually assumed to be in need of counselling. The Spinal Injuries Association (SIA) are the national organisation of people with SCI and offer a counselling service for members that is provided by fully trained counsellors, who themselves have SCI. Therefore it seemed likely that SIA members will have been offered counselling at some point since they became disabled and represent a valuable source of people who may have had experience of several different counsellors e.g. counselling within a spinal injuries unit (SIU) as well as SIA counselling. I gained the support of SIA to undertake this research and an article was published in the March/April edition of the SIA magazine *Forward* describing my study and asking for volunteers to contact me if they were interested in taking part (see Appendix 1). It was important that participants were not currently seeing a counsellor because it would be unethical for my questions and the issues they raise to risk jeopardising a current counselling relationship.

I had hoped to generate a volunteer sample (Seale and Filmer, 1998) which was large enough to choose six participants who represented a range of stratifying factors such as age and gender, based on the results of a small quantitative questionnaire (see Appendix 2). However after I had rejected one participant because he had just started seeing a new counsellor, I was left with five possible participants and the questionnaire instead served to supply me with some basic information about my participants. Four of the participants were white (UK/Irish) and one person came from North America. The questionnaire did not ask whether people had seen a counsellor or psychologist but this information came out during the interview. For the purposes of this study I will be considering the counselling skills and

approaches used by a psychologist *or* counsellor and will ignore any other differences between the two groups of professionals.

Here is a short biography of each participant:
- Fred is aged 26-35 and was injured 6-10 years ago. He was referred by his GP shortly after his accident to a counsellor who he saw a few times at the counsellor's house with his wife Pearl. Over the last two years he has seen a psychologist at an SIU occasionally. Pearl was present at the interview.
- Harry is aged 56-65 and was injured more than thirty years ago. He first saw a counsellor at his GP practice shortly after his injury. He then saw a second counsellor at her house 11-20 years ago. Finally he saw an SIA counsellor 1-2 years ago who visited him at home. Each period of counselling lasted 1-2 months.
- Jane is aged 36-45 and was injured more than thirty years ago. She saw a slightly disabled counsellor once within Social Services about twenty years ago. She also saw a psychologist twice at an SIU around the same time.
- Max is aged 36-45 and was injured 6-10 years ago. He started seeing a counsellor on his own initiative a couple of years after the accident and saw her for over two years at his house. Max's fiancée Poppy was present at the interview.
- Steve is aged 56-65 and was injured more than thirty years ago. He has seen two psychologists privately during the last two years each for 3-6 months. He saw the first psychologist at her house, and the second one in his own home.

Whilst advertising for my participants in *Forward* was convenient, within my time-scales and free, this meant that my data sources were limited to people with SCI who are also members of SIA. One result of this sample choice means that there will be an over-representation of people who became disabled through injury rather than illness which also tips the gender balance in favour of men (Morris, 1989); all my participants acquired SCI through injury rather than illness. My gender ratio of one woman to four men matches the ratio of people admitted to hospital following injury (Kennedy, 1998). However the SIA membership of 4500 people (out of 41,360 people in the UK with SCI (ICCP, 2000)) has a ratio closer to one woman to three men (SIA, 2000). Given the small numbers in my sample I can only comment that my participants represented three out of four of the highest membership age ranges. There is no reliable source of SCI statistics in the UK (SIA, 2000) and SIA are still in the process of analysing a membership questionnaire that was circulated nine months ago. Therefore I do not have any data on the ethnic background of people with SCI in the UK and cannot comment about how representative my sample was in this respect.

Data Collection

Within this emancipatory research I used a modified version of Barnes' (1992) 'three-stage' approach to interviewing to return as much control as possible back to the participants. The first stage is critical in ensuring that people understand what the research is about so that they are giving their *informed* consent to take part in this study. I adopted a similar strategy to Priestley (1997) and provided the participants with the following information:
- Information about the project which included information about me, the research project and various issues such as confidentiality (see Appendix 3)
- Draft of the interview topic guide together with a feedback form (see Appendices 4 and 5)
- Questionnaire about interview availability which also gave participants the chance to choose their own pseudonym (see Appendix 6)
- A consent form to be signed by myself and the participant once they were happy to proceed (see Appendix 7)

This process of consultation about the areas to be discussed does help return control to the participants; additionally it ensures that the agenda behind the interviews is relevant to the participants, rather than being just my own personal agenda. I will discuss the problems with this method later.

I also carried out a pilot interview to obtain feedback on my interviewing skills and to see how it felt to interview within the broad areas of the interview topic guide (Seale and Filmer, 1998).

I then went on to the second stage in which I carried out focussed interviews with participants (May, 1997). In preparation for the interview I sent more information to the participants:

- The final version of the Interview Topic Guide (see Appendix 8)
- Information about the interview and how it would proceed (see Appendix 9)
- A statement reinforcing people's freedom to choose how much they wanted to discuss with me (see Appendix 10)

The interviews were carried out at people's homes or by telephone and were taped with the participant's permission. Taping the interviews meant that I could note any significant non-verbal communication as well as facilitate the discussion through active listening (May, 1997). I used the interview topic guide to introduce each of the areas I was interested in and then allowed the participant to explore that area in as much detail as they felt comfortable with. The detailed questions on the topic guide were only used when participants felt 'stuck'. The use of the topic guide enabled me to apply a loose structure to the interview to prevent it turning into a counselling session (McLeod, 1994), but remained loose enough to allow the participants control over what they chose to share. My counselling skills were invaluable in carrying out interviews in a way which was respectful, supportive and facilitative (Skinner, 1998) and I used appropriate self-disclosure to facilitate trust between my participants and myself (Vernon, 1997). However my training in empathic listening did cause me some difficulties which I will discuss further in Chapter Six. In addition to this I produced an information sheet about how to access a counsellor (including the SIA counselling service) and a short list of books for further reading (see Appendix 11). This information was offered to participants when appropriate after the interview and was accepted by one participant.

The third stage of the interview process gave participants an opportunity to see a complete transcript of the interview (using their chosen pseudonym and with identifying details removed) and they were encouraged to return any comments to me (see Appendix 12). One participant changed my literal translation of his accent and two others felt they had 'said more than they had realised' and asked for a couple of small sections to be changed or removed. Whilst this three-stage model helps move control back into the hands of the research participant, it also involves a lot of time and energy for my participants and me (Zarb, 1992). Therefore although people were given the chance to comment on the interview guide and interview transcript, there was no compulsion to perform these tasks.

As my sample was small and restricted to people with SCI who are also members of SIA, the conclusions from this research may not be applicable to all people with SCI or disabled people in general. However it will be able to suggest directions for further study. The use of an interview guide provided a measure of reliability for my data collection (Silverman, 2000). As *Forward* is a national magazine, my participants came from all over Britain. I interviewed one person by telephone (his preference) and travelled to interview the other people face-to-face in their own homes because my home is inaccessible. This difference in method did not appear to adversely affect the data I collected. I am accustomed to counselling face-to-face and by telephone; the anonymity provided by the telephone enabled that particular participant to talk about their issues more fully, increasing the validity of their data. The decision to use material from past counselling relationships may affect the validity of the results because participants may offer a reconstruction of their counselling experiences rather than direct description from tapes of sessions (McLeod, 1994). However the study by Oliver (1995) used this approach successfully and I felt justified in my decision to respect current counselling relationships. I attempted to improve the validity of my findings by encouraging feedback from my participants both before and after the interview. On reflection I am not convinced that this 'member validation' worked, for the same reasons given by Bloor (1983, in Silverman, 1985; 44), although participants commented that they felt involved in the process.

Data Analysis

The tapes were transcribed in full to avoid any bias in the subsequent analysis (Silverman, 2000) and identifying information was changed. Once the transcripts had been agreed by the participants, I used an eclectic approach to analyse my data using ad hoc methods (Kvale, 1996; Ch.11). Firstly I gained an overall impression of each interview by re-reading each transcript several times. I then coded each interview using categories which originated from the interview topic guide and added new categories as required. The interview coding process

was repeated using this new 'complete' list of categories to ensure that all interviews were coded in the same way, indexing by date and line of interview transcript. The list of six main categories together with their sub-categories is provided in Appendix 13. I was then able to review the categories looking for similarities and differences in the experiences and thoughts of my research participants. I found this process invaluable for highlighting connections and structures which were otherwise obscured by the amount of data I had collected (6 hours of transcribed interviews which was about 60,000 words).

My data analysis has been validated in three ways to avoid rejection of my results on the basis of 'anecdotalism' (Silverman, 1993). The method of coding I adopted meant that my data has been subject to the constant comparative method, and by implication, a comprehensive data treatment in which all parts of the transcripts have been inspected and analysed (Silverman, 2000). The second way in which I attempted to validate my results was by sending an accessible summary of my findings to each participant which included their quotes and personal information I intended to use in this dissertation (see Appendices 14 and 15 for the summary report with all quotes and associated feedback form). As already mentioned, this method of member validation has problems and it was more useful as a means of giving back control to the participant rather than validating my findings although I did receive confirmation from all participants that they agreed with my findings. I decided not to validate my results by including copies of the transcripts with this dissertation (Silverman, 2000) because I would have no control over how this sensitive material would be used by others. A final validation of my results will be to compare my conclusions with the results of research by Oliver (1995) and Lewis (1997).

Ethical Considerations

This research spans both disability studies and counselling and I have been following ethical guidelines and codes of practice produced by the British Sociological Association and the British Association for Counselling (BSA, 1993; BAC 1996a; 1996c). I have had counselling supervision throughout the interview and analysis process. This has allowed me to prevent one particular interview turning into a counselling session after the participant revealed a past incident of child abuse before the interview (Kvale, 1996). I have also needed supervision for my own support because the issues being discussed have been very relevant to me personally, raising a lot of my own emotional issues (McLeod, 1994). The use of a personal research diary, together with supervision has helped me keep my own issues separate from those of the participants and has also challenged some of my own attitudes which could have otherwise affected the interview process (Scott, 1999). Confidentiality has been a very important issue to several of the participants and I have been clear throughout, about my responsibilities towards participants and the ways in which I will use data generated by the interviews for reports and future publications within disability studies and counselling (see Appendix 3).

Difficulties Encountered during Data Collection

I experienced the usual problems which all interviewers suffer - technical problems with the recording equipment which meant I lost 15 minutes of one interview and intrusive background noise which is only noticeable when the tape is being transcribed! My main difficulties occurred when I interviewed Max and I will now describe those in more detail.

In two of my interviews the partner of the participant also attended. In the case of Fred and Pearl this worked well as Fred felt more able to speak with Pearl present. When I interviewed Max, his fiancée Poppy was also present and her presence significantly affected the interview. As the interview progressed I noticed that Max's answers were becoming shorter and Poppy's body language was gradually closing up – at one point she had her head on her arms. I did not understand what was happening until an argument started between Max and Poppy when I stopped to turn over the tape in the tape recorder. In the heated discussion that followed it emerged that Poppy had been very unhappy with the counsellor Max had been seeing, because the counsellor had been a wife of his best friend. After this argument it became very difficult for me to continue asking Max about his counselling experience as it

placed him in a dilemma – did he give information he felt I wanted to hear (Silverman,1997), or did he provide the answers which supported Poppy?

My data analysis has treated my interviews as a resource rather than a topic in itself (Seale, 1998) and so the contradictory information about Max's counsellor led me to discount this information from my analysis (Kvale, 1996). I have included the rest of the interview in my data analysis but appreciate that Poppy may still have been influencing what Max was saying. This was a very good example of an interview where my presence as a visibly disabled woman who was also a counsellor had a significant effect on the interview process (Scott, 1999). This was also the only interview where I was extensively questioned and challenged about my own identity as a disabled woman and I later wondered if this reflected Max's uncertainty about his own identity as a disabled person. Whilst this particular interview would benefit from an analysis as a topic in its own right, it is outside the scope of this dissertation.

Summary

From the above discussions it can be seen that the study was completed with relatively few problems. This was due to the excellent support I received from my counselling supervisor together with helpful suggestions from other MA students and tutors. My participants worked hard and they have been generous with their time, honesty and energy. I worked hard to develop relationships with my participants and to be honest with them from the outset; my counselling skills and personal reflexivity certainly helped with this process, although it did cause me some problems that I will discuss further in Chapter Six.

I acknowledge that five participants is not a large sample and I will not be able to make any grand claims from this research. However I hope that the quality of the data generated will allow suggestions for future research to be made. Whilst some of the counselling experiences took place over three decades ago, I still consider these to be a valid source of data as they document ways in which disability and impairment can be approached within counselling. In the next three chapters I will discuss this data further and develop the arguments outlined in Chapter One.

Chapter 4

Disability and Impairment within Counselling Relationships

In this chapter I will consider how disability and impairment issues (those that affect activity and emotional well-being) were understood and negotiated by the counsellor and disabled client. I will look at how these negotiations affected the quality of the counselling. In the next chapter I will look at how helpful counselling is for people with SCI and explore suggestions for the future.

I had naively assumed that as my interview topics were clearly about the separate areas of impairment, disability and the psycho-emotional element of disability, I would gain clear insights to how these topics were understood and discussed by counsellor and disabled client. In reality, the topics were closely interwoven. One difficulty is that people's understanding of the difference between disability and impairment is muddled (Thomas, 1999a). I had also failed to appreciate the extent to which people's experiences of disability and impairment, both with respect to restrictions on activity and effect on psycho-emotional well-being, would be intermingled as described in Chapter Two. Serendipitously, this 'muddle' allowed me to generate data about the emotional effects of impairment that I had neglected to include as a separate topic in the interview topic guide.

Despite the wide range of participant experiences I did find considerable commonality between the interviews which will be discussed further in this and the following chapter. All of the research participants had first entered counselling because of an impairment related problem; this was in response to becoming SCI (about 1-2 years after the event) or following a deterioration in the condition many years later. This supports the observation that people with SCI want access to counselling at various times in their life and not just post-injury (Trieschmann, 1988; Oliver et al., 1988). In contrast only one person also went to counselling to discuss an aspect of disability. Whilst disability, structural or psycho-emotional, was not the presenting issue which the other participants people took to counselling, it was discussed by everyone at some point within the counselling, although they might not have realised this at the time.

Because of the manner in which disability and impairment cannot be broken neatly into theoretical compartments (Thomas, 1999a), I will present my findings by considering the main disability and impairment issues which each participant had taken to counselling. For a brief biography about each participant, please refer to pages 47-48 in the previous chapter. I will show the complex interconnection between impairment and disability described by each participant and the ways in which counsellor responses affected the outcome of the counselling.

Jane

Jane talked to her counsellor about her increased impairment following botched abdominal surgery and osteomyelitis compounded by a doctor who would not listen to anything she had to say about her own body. Medical practitioners often fail to understand the full implications of SCI and so misdiagnosis of unrelated conditions is not uncommon (e.g. Beth, cited in Morris, 1989; 173). Jane described what she wanted from the counsellor:

> 'And all I wanted, and I – I, was somebody to say - to listen to me and say "Yes, you're right to be angry", but allow me to go through - I mean I understand it now better than I did then but I think all I wanted was somebody who wasn't going to get fed up with me talking for a few, for a few sessions until I could just settle down to the fact that actually yes, that had all happened to me, nobody was going to tell me that it hadn't happened and that when I was ready to then move on - I could move on. But he, he wasn't wise enough or knowledgeable enough to understand that sometimes that's all people want, they don't want, there isn't a cure' (Jane).

However the counsellor insisted that what Jane needed was a second opinion from another doctor and he offered to find out information for Jane about osteomyelitis. This counsellor was failing to listen to Jane, like the doctor, and to make matters worse he never got back to her with the information he promised. Jane was talking to her counsellor about impairment and the emotional effect it was having on her. The emotional aspects included her feelings as she accepted how her impairment had changed, but also feelings of anger about the way in which she had been treated by her doctor and the hospital. The counsellor, like the doctor and hospital, were adopting attitudes consistent with the medical model of disability in which impairment is to be cured, which was not what Jane believed.

Jane felt that the message she was being given was:
> 'That there's no space for you if there's no cure, sort of thing - you know, that, that they didn't want you in hospital because there was nothing more they could do … they only had time for people who actually they could do something about. … I was searching desperately for just somebody to have time for me - nobody had time - and that was what I was looking for in the counselling session' (Jane).

This dismissive and patronising attitude of doctors towards disabled people who cannot be cured (French, 1994c) had left Jane feeling worthless. The counsellor had reinforced this psycho-emotional dimension of disability by his failure to listen to Jane and his insistence that she obtain a second opinion fuelled by his prejudice that disabled people always want to be cured (Morris, 1991). It is interesting that the counsellor was disabled himself (or at least had an impairment) and appeared to have a very different view of impairment and disability to Jane. I will discuss this point further in the next chapter. By contrast the psychologist she spoke to at the SIU *did* listen to Jane and acknowledged that anger was a valid response to what had happened, reducing the negative affect the hospital experience had caused.

Fred

Fred and Pearl talked to their first counsellor about the early problems they had learning to manage Fred's urinary incontinence.
> 'I was having trouble coping with Fred being incontinent. Fred was having trouble coping with Fred being incontinent, and if we talked about that she said that you have to listen to each other. Huh, I don't want to fucking listen to him, I want to not have to get up in the night to empty a pee bag – I'm tired, I'm sleepy' (Pearl, Fred's wife).

Parker (1993) found that providing intimate personal care of this nature is problematic for both people within a relationship. The counsellor ignored how this aspect of SCI was emotionally affecting Fred and Pearl and instead attributed all the couple's problems to marriage failures. This counsellor also refused to listen to the disability problems the couple were facing - social exclusion and the:
> '… colossal social pressure [for Pearl] to conform and be a martyr and look after Fred' (Pearl, Fred's wife).

Disability problems were also interpreted as marriage problems and eventually disability became a taboo, the 'D-word' (Fred). Her refusal to engage with Fred as a disabled person extended to the condescending manner in which she grudgingly admitted Fred into her inaccessible house; as a wheelchair user he needed to be carried in and then once inside she made a show of needing to move furniture in order to accommodate him. This made Fred:
> '… feel like shit. Here I'm supposed to be being helped, and I am just being made to feel more in the way … [she] spoke mainly to Pearl… it was very much "Does he take sugar" thing, and from a counsellor which was, not good - no. We haven't seen her anymore, funny enough' (Fred).

Pearl and Fred were discussing issues about impairment and disability, how these affected how they felt, as well as the impact on what they could do. Whilst this counsellor claimed to have experience of counselling disabled people Fred and Pearl felt that she had no experience of counselling people who have sudden traumatic injuries and was 'out of her depth'. Instead of acknowledging her lack of knowledge and seeing them as 'experts' which would have been empowering for Fred and Pearl (Oliver, 1995), she refused to engage with these issues and reinforced the message they were receiving from other professionals – 'to put up and shut up' (Pearl). Fred and Pearl were upset at the way society excluded them, now that Fred had become disabled (Keith, 1996). The counsellor, with her prejudices about

disabled people (e.g. that Fred could not speak for himself) added to the psycho-emotional aspects of disability they were already experiencing.

Fred has seen a psychologist at an SIU more recently who has been much more helpful. Fred was able to talk to this person about incontinence and the way it made him feel and he described the following incident:

> Fred: 'On one visit I pissed myself in the car on the way up and I tried to change my sheath and saw piss flying everywhere around the car, I was really pissed off as you can imagine, and er I was saying to [the psychologist], "I feel really dirty and pissed off about this" and he says, "Bugger me - I thought it was part of spinal injury", and then he say …'
> Pearl: '….. he said he have to go and tell the other patients - all his patients - they weren't spinal injured, just stupid and they could pull themselves together and get over it!'

Fred found the way that this psychologist responded to him about incontinence helped him keep the difficulties in perspective and found it very helpful that the psychologist was able and willing to allow Fred to talk about the 'dirty' aspects of incontinence which are denied a voice elsewhere. Fred also felt that the psychologist acknowledged the emotional effects of incontinence, the humiliation and sense of shame, at the same time as allowing it to be talked about as a practical issue. Whether or not this humiliation and shame is a psycho-emotional effect of impairment or disability is debatable. There are powerful social pressure and cultural codes to be continent (Cavet, 1998; Marks, 1999b); however there are also suggestions that there is an evolved disgust of bodily fluids because of the association with disease (C4, 2000) and this could therefore have *personal* emotional implications for someone who is incontinent.

Steve

Steve tried to talk to both his psychologists about his frustration at not being able to do the things he used to be able to do since he had lost much of the use of his hands. His counsellors seemed unable to understand this link between frustration and impairment, preferring instead to look at past and present relationship problems for a cause of the frustration.

> 'And I don't want people to grab me, because that gives me a spasm. And a spasm, a spasm can throw me out the chair. So you get to the stage after a while where, you don't – it's not as though you don't want to be touched, there is an implication that touching – and it's bad news. It's not good from a relationship point of view, but it's a fact of my life – I can't get away from that. …. Um, if she'd [the first counsellor] understood the disability [sic] aspect of it, she would have understood why, that happened. But she didn't, she says "Alright, I'm a psychologist, so therefore people who don't like being touched, there's got to be some deep-seated psychological reason" ' (Steve).

The psychologists also interpreted Steve's reluctance to go out for the evening with his girlfriend as being due to relationship problems, instead of the very real difficulties that Steve experienced in accessing the built environment (Barnes, 1991). This was probably due to the fact that both psychologists worked within a psychodynamic framework in which all psychological problems are assumed to be down to problems with past relationships and childhood development (McLeod, 1998). Steve found the inflexible approaches of these two psychologists very annoying and as a result the counselling he received was unhelpful (Luborsky et al., 1985).

Whenever Steve tried to talk about disability it became obvious that the psychologist did not really appreciate what he was describing and certainly did not understand the implications of living with disability 'all day and every day'. Whilst Steve admitted that he had always been intolerant of people before the accident, his continual frustration with inaccessible buildings and other people's disablist attitudes had made him more aggressive and intolerant. Again the psychologist failed to understand this link between aggression and disability and instead offered an explanation related to a childhood event - an interpretation which Steve found very unhelpful. This failure to understand anger as a natural reaction to the experience of living in a disabling society added to the repression that Steve was already experiencing (Ley, 1994) –

an example of oppression in the counselling room. This is also an example of a professional individualising a problem that is actually a societal one, as described in Chapter Two.

Harry

Harry first saw a counsellor soon after his accident, in the 1960's. He talked to her about the social isolation he was experiencing and about sex and girls – as a young man in his 20's these were important issues for him and his SIU had not provided any sex counselling after the accident (Oliver et al., 1988). Every time he tried to talk about sex or girls, she would change the subject.

> ' "Oh, you've got enough to think about, you know", um, um, without thinking about that. I said, "Well, sex is important to me". She – good Lord – she said, "You'll probably find, you'll bump into a disabled girl sooner or later" ' (Harry).

It is relevant to remember that this was the 1960's and Harry described this counsellor as very 'matronly'. So it is not surprising that sex was taboo and not to be discussed – the sexual revolution of the 1960's was only just beginning (Haste, 1994). In addition, it was only in the 1960's that disabled people were starting to live in the community instead of being hidden away in institutions (Barnes, 1991). Her prejudices that disabled people were asexual and would only form relationships with other disabled people are not uncommon today (Morris, 1991) but are more understandable given the absence of disabled people within society at the time this counselling took place.

Like many disabled people, Harry had experienced 'public stripping' in hospital (French, 1994c) and this had seriously undermined his self-esteem in the ways described previously in Chapter Two – he felt very self-conscious about his body and was concerned about how a woman would feel towards his impaired body. Oliver et al. (1988) reported that men did feel embarrassed about their bodies and worried about their sexuality. This was particularly true in the case of young men, one of whom said:

> ' "The sexual side does bother me. It's the worst thing about being in a wheelchair. It does you in mentally" ' (Oliver et al., 1988; 50).

Coupled with his experiences in hospital, the denial of Harry's right to be a sexual being and to have a relationship with a non-disabled woman was disastrous – he was made to feel like a 'pervert' and this shame and guilt stayed with him for the next thirty years. A similar experience was found in the study by Morris (1989) of women with SCI:

> ' "I was made to feel "crude" or labelled sex-mad because I wanted to resume a normal life. It appeared that, once disabled, it was wrong to think of sexuality – disabled people didn't do that kind of thing!" ' (Pauline, in Morris, 1989; 80).

The attitudes of the first counsellor made Harry feel much worse about himself as he had internalised her prejudices about the sexuality of disabled men.

Many years later Harry sought help from another counsellor who was much more aware of SCI and disabled people. He did talk to this counsellor about incontinence issues and she was able to offer him information and advice about product sources, sharing information from other disabled people she knew with the same problems. As a result Harry was able to change to a different brand of sheath which caused him less problems and made life more comfortable. However Harry was frightened that if he told her about his desires for a relationship, that she would also regard him as a pervert. It upset Harry that he couldn't open up to this counsellor who was being so understanding and sensitive with him about the other issues he talked about.

It was not until thirty years after seeing the first counsellor that Harry accidentally found a disabled counsellor who had SCI and was also married. He felt he could trust her and when he told her about his desire for a sexual relationship, she responded by saying:

> ' "I haven't known a man who doesn't think like you. So you're not – there's nothing perverted, nothing" ' (Counsellor to Harry).

Seeing this counsellor (who also happened to counsel for the SIA) was a huge turning point in Harry's life. He was able to stop feeling perverted and finally to experience sexual relationships with women. Both of these last two counsellors saw Harry as a sexual being, but it was the fact that he saw the last one has having inside 'knowledge' because she was disabled (Withers, 1996), that was the final key to him trusting someone enough to talk

frankly. Unfortunately the prejudices of the first counsellor together with his experiences in hospital have left their mark on Harry and he still feels ashamed and guilty about his sexuality at times. He also struggles with the clash of stereotypes – disabled people as passive and dependent versus men as powerful and in control (Shakespeare et al., 1996).

Max

I will not include Max in this discussion for the reasons discussed at the end of the previous chapter, although he did comment that he felt that his counsellor, who was a feminist, did understand the experience of being part of an excluded group within society.

Discussion

These 'narratives' show the complexity of disability and impairment issues, the way that the psycho-emotional effects are mixed with the structural elements of disability and the physical problems associated with impairment. All of these people talked about aspects of the emotional dimension of disablism – feeling worthless and 'in the way', being stressed by external barriers and feeling ashamed of one's sexuality. Unfortunately all of these people also experienced counselling which was oppressive with the counsellor's (or psychologist's) prejudices and attitudes reinforcing the negative feelings they already had about themselves; in many respects I would suggest that the counsellor added to the internalised oppression already experienced by that person. This can be compared to the helpful counsellors/psychologists seen by Harry and Fred who held positive attitudes towards disabled people and held a social model view of disability. Despite the fact that some of these counselling experiences took place over thirty years ago, they still provide a salutary lesson about the powerful ways in which counsellor prejudice can effect the outcome of counselling.

The most common emotional difficulty about impairment was that associated with the embarrassment of incontinence and was discussed by three participants. People found it very helpful to be able to talk about this taboo subject and found it useful when the counsellor kept the problem in perspective and was able to offer practical suggestions to solve practical problems. Counsellors and psychologists who had knowledge of SCI (e.g. worked within an SIU) appeared to be able to offer the most positive support to this group of people. As everyone is familiar with the experience of embarrassment and humiliation, it may be that counsellors find it easier to empathise with the emotional dimensions of impairment than those of disability.

These results also show that people with SCI want to talk about their experiences of disability *and* impairment, that both areas are important to their lived experience. Incontinence is a common result of SCI (Kennedy, 1998) and given the huge emotional effect on people who manage this problem, it is not surprising that this taboo issue would be discussed within counselling. This then raises the question about whether people with other types of impairment, which have more socially acceptable consequences, would also want to discuss impairment within counselling. Further research is needed to address this question and how it fits theoretically with the debates mentioned in Chapter Two about whether or not the social model of disability acknowledges the role played by impairment and illness in the life experiences of disabled people.

Finally I believe that it is significant that all my research participants discussed their experiences within SIUs and the ways in which they had ended up feeling embarrassed, humiliated and ashamed as a result of the way they had been treated by the medical profession. These experiences spanned the 1960's to the early 1990's and so are not just a relic of 'the old days'. It would appear that the experience of being in an SIU can be disabling from a psycho-emotional aspect and this would be worthy of further research. Pearl described how it had felt in the SIU where Fred had been treated:

> 'They were just rolling bags of bones, and clean the shit off the bag of bones - they weren't dealing with people. It is one of the most humiliating environments I have ever seen' (Pearl, Fred's partner)

Not only does rehabilitation need to address the physical *and* emotional needs of people with SCI (Oliver et al., 1988) but it should not *increase* the emotional difficulties of these people.

Summary

I have shown the way in which my participants experience of impairment and disability is complex and conjoined – it is not always possible to separate the practical from the emotional, the social from the biological (Thomas, 1999a). It can also be seen that the counsellor's view of disability had a huge effect on the counselling experience; counsellors with negative attitudes and prejudices about disabled people further oppressed their disabled clients, making them feel worse about themselves. Additionally counsellors who had knowledge about SCI and its effects were useful and their clients valued the information they could provide.

I will now look at some of the other aspects of the counselling experiences reported by my participants in the next chapter and consider suggestions for the way forward if counselling is to be an empowering, rather than oppressive, experience for people with SCI.

Chapter 5

Counselling People with SCI – now and in the future

In the previous chapter I discussed the different responses participants with SCI had when talking to counsellors about impairment and disability issues. I have discussed the ways in which counsellor's attitudes towards impairment and disability affected the outcome of the counselling – whether it was empowering or oppressive. I will now explore the other factors which affect how helpful people with SCI found counselling in dealing with disability and impairment related issues, together with suggestions which would improve future counselling experiences for this particular client group.

Issues for counselling theory

I did not ask people explicitly what counselling approach their counsellor or psychologist was working with, as clients do not always know this information; I deduced the theoretical orientation of the practitioner by looking at the interventions they had offered. As discussed in the last chapter, both of the psychologists that Steve saw were working within a psychodynamic approach which he did not find helpful as they failed to recognise the social causes of disability (Lenny, 1993). The psychologist seen by Fred at the SIU worked within a cognitive-behavioural orientation and used a practical, problem solving approach to give back control to Fred; the approach was simple enough to be used by all people with SCI including small children. The other psychologist and all the counsellors worked from within a humanistic approach. It is difficult to draw any conclusions from this small sample of counsellors and psychologists. It is possible that the counsellor or psychologist themselves was not particularly proficient at counselling per se and so it was not the counselling approach which could be blamed for the failures in the counselling. However it would appear that the qualification of the practitioner – whether they were a counsellor or psychologist – did not affect the outcome of the counselling. This is despite the fact that a psychologist usually has a much more rigorous academic training than a counsellor (Davidson and Davidson, 1997).

In Chapter Two I showed that counselling theory generally advocates the use of 'loss' theories to explain how disabled people will 'adjust' to disability but I found that only two participants mentioned any concept of 'loss' in connection with their counselling. In both cases the description of loss offered by the counsellor or psychologist was only mentioned in passing, and neither person found it particularly helpful. I found it surprising that the 'loss' models were not more present given the high profile they are accorded within the counselling literature for people who acquire impairments.

There was a general consensus that people wanted counselling to provide a space where they could 'talk out' their feelings about SCI and disability without judgement. However they then wanted counselling which was a bit more directive, which would help them move on with their lives and find solutions to the daily problems of living.

> 'And one thing that doesn't work, is this "give people space" business. There has to be some direction to it, 'cos - what was it [the psychologist] said – "The general idea is to get you back to normal life, or at least normal for you", so that you can't - nobody can afford two years clambering around in a morass of upset feelings. Somebody has to say "This is the way out of this one - it's worked for other people - if it doesn't work for you, we'll find another path, but this is the way most people find helpful" ' (Pearl, Fred's wife).

So, when working with people with SCI, a counselling approach which is more focussed on solving problems, such as cognitive behavioural or brief therapy (McLeod, 1998), may be more beneficial than a pure humanistic approach in which the counsellor is completely non-directive. A problem-solving approach would also lend itself to include the teaching of specific skills such as assertiveness, to enable clients to make changes and to regain control over their lives. This finding may be applicable when counselling other groups of disabled people

as Oliver (1995) concluded that counselling should aim to enable disabled people to empower themselves.

As discussed already, it was the theoretical viewpoint of disability held by the counsellor or psychologist which had the greatest effect on whether the counselling was helpful or not for looking at disability and impairment issues. All of my participants felt it was vital that the counsellor understood the ways in which society disabled them and saw disability from a social model perspective. Jane described how she would have found it helpful if her counsellor had challenged her gently to help her move out of the 'rut' she had got stuck in:

> 'And I think that's maybe what - what somebody should have - should have said back, and took me away from this concentration on impairment and actually challenged me to say well "That's what - that that's a fact. All those horrible things that happened to you" - had - had - had you - if I had - if somebody had come at me with a social model to try and move me away from getting blocked in to that medical …' (Jane).

I described earlier the findings (Oliver, 1995) that counselling reflections framed within a social model viewpoint were empowering for disabled clients and it would appear that the same is true for this small group of disabled people. A counsellor working within the social model of disability could also raise awareness of the common, disablist problems which people with SCI (or any other impairment) face in society. I believe research is needed to consider how some of the newer counselling approaches such as brief therapy compare to more established approaches when working with different groups of disabled people. It would also be interesting to see if integrated or eclectic counsellors who work within a variety of theoretical approaches are more effective than those who work within one orientation.

In Chapter Two I disagreed with the conclusion made by Oliver (1995) that disabled people do not need different counselling to non-disabled people. My small study of people with SCI has shown that they want counselling which helps them 'get out of ruts' and solve practical problems. I have also shown the huge negative affect that counsellors can have on their disabled client if they view impairment and disability as irrelevant (Steve) or fail to consider the emotional effects of disablism (Harry). I believe that more research is needed to explore which counselling approaches are most helpful for people with SCI and other impairments, drawing on the experience of counselling approaches used with other oppressed groups in society (Reeve, 2000).

Access and choice of counselling services

Access to counselling services had been difficult for many of my participants. Steve's choice of psychologist was based on accessibility criteria; even so, he had to use his own ramp to access the house and his sessions were held in her lounge because her counselling room was upstairs. This room was not heated adequately in winter and often had her child's toys scattered around; as a result Steve felt he was being grudgingly accommodated, much like the experience of Fred in the last chapter. The practical issues of providing counselling from home have been discussed elsewhere (Burridge, 2000) and it is important that everything possible is done to achieve a respectful counselling space for the client. Max had never been offered counselling by his SIU and this was one of the reasons why Max ended up having a counsellor who was also a friend – he had no other choice of emotional support - but this 'dual' role caused problems in the counselling relationship because it compromised boundaries (McLeod, 1998). I was unsure how helpful Max had really found this counselling and it raises questions about the different forms of support which can be offered by friends as opposed to counsellors (Feltham, 1999). This counselling relationship may well have been a replacement for friendships in society as described in Chapter Two, which begs the question whether this happens more frequently for disabled people who lose non-disabled friends after they acquire their impairment (Oliver et al., 1988; Morris, 1989). The issue of friendship versus counselling for disabled people is worthy of further research.

Participants felt that SIUs should offer counselling to all their patients with SCI, and not just the ones who appeared to need it (Kennedy, 1991). Fred also commented that this counselling should be available on demand, and by self-referral without needing to involve the GP. Whilst this could be helpful for people within easy reach of an SIU, others would need, or prefer, access to community counselling services. Harry raised the problem I discussed in

Chapter Two about the lack of accessible counselling services for disabled people compounded by the lack of accessible public transport.

> 'Locally as well, they shouldn't have to sort of speak to somebody in London, or – they should, I mean … I don't know whether Relate, I mean, they say they counsel disabled - but I don't know, but um. I just know, well you see I mean, our – my - our nearest Relate is in [town] which is, say fifteen miles away. But I mean, you've got to get over there and back which is not easy. I can't use public transport, I don't drive anymore now, so um, how do you get over there? They don't even have taxis which takes a wheelchair 'round here, you see, so you're – so I mean that's another problem.' (Harry).

Counselling services need to comply with the law and provide counselling which is accessible for disabled people - non-disabled people would not be willing to accept telephone counselling with a counsellor in London as their only counselling option. Several of the participants had seen the counsellor in their own home, which generally worked well although not all counsellors were willing to provide this service.

I was also interested in people's views of disabled and non-disabled counsellors. Two of the counsellors seen by my participants were themselves disabled, although this had not been the criterion for selecting the counsellor. Jane's counsellor was working from a medical model approach to disability, whereas Harry's SIA counsellor viewed disability as a problem caused by society. The first counsellor made Jane feel worse about herself whereas Harry found his counsellor very helpful. There are two possible explanations for these differences. One possible explanation for the problems Jane encountered is due to the fact that she held a different view of disability to her counsellor. It has been shown that counselling works most effectively when counsellor and client have the same viewpoints (Roth and Fonagy, 1996). In this study all my participants saw disability as a problem created by society and the most helpful counsellors/psychologists shared this viewpoint. Whilst I agree with Oliver (1995) that counselling is more empowering for disabled people if a social model approach is adopted, and that this is probably the explanation for the different experience in this case, it would be interesting to explore how helpful counselling is when both counsellor and disabled client see disability as an individual (medical) problem. This particular study did not have an example of this dynamic.

I asked my participants about whether or not they would prefer to have disabled counsellors in the future and was surprised that the disability status of the counsellor was considered to be relatively unimportant. All my participants said that the most important characteristic of the counsellor was that they had no emotional baggage of their own about disability. It was felt that the potential gain of having a disabled counsellor with similar experience and hence empathy, was weighed against the risk of them having their own unresolved issues about disability; this reflects the concerns discussed in Chapter Two. Poppy had concerns about counsellors generally, and voiced a concern Max had already talked about before the interview:

> 'Um, 'cos you know - you as a counsellor - a disabled counsellor being disabled yourself, you might be having some really big chips on your shoulder anyhow, and instead of helping this newly disabled person, you're sort of verbally giving them your chips on your shoulder – "Do have a plateful of my chips!" ' (Poppy, Max's fiancée).

This fear about disabled counsellors could also be a form of internalised oppression leading to the belief that disabled counsellors cannot be as 'good' as non-disabled counsellors (Ratna, 1994). A similar fear has been found when the counsellor and client are both gay (Mair, 2000) or Black (Rose, 1997). Given how few disabled people train as counsellors, it is perhaps fortunate that my participants do not believe that counsellors have to be disabled to counsel them.

Issues for counselling practice

My study shows that in addition to understanding disability correctly, the counsellors and psychologists who were most helpful to my participants with SCI had knowledge about SCI and its effects – one counsellor had SCI, another had worked with a lot of people with SCI and two psychologists worked in an SIU. All my participants felt that it was essential that counsellors should know about SCI if they were going to counsel this particular client group.

Whilst my sample is not large, the result is significant enough to suggest a link between counselling effectiveness and the SCI knowledge of the counsellor or psychologist. Lewis (1999) also found that counsellor effectiveness when working with people with MS was improved if the counsellor understood the implications of having MS. This is no different to counsellors working in the fields of transcultural counselling or any other specialism where it would be expected that the counsellor would be knowledgeable about the issues relevant to that client group (Lago and Thompson, 1996). This link between counsellor knowledge about impairment and counsellor effectiveness is another area which would benefit from further research.

There are several aspects to this knowledge about SCI that are important. The counsellor needed to be comfortable talking to their client about all the effects of SCI including the 'taboo' subject of incontinence.

> 'But if there was a counsellor there for him that could do this with him, that says, "This pisses you off to piss yourself dunnit", somebody that's quite happy to do that, something that will hit it, you know, on like that …' (Poppy, Max's fiancée).

People also valued information and advice which the counsellor could provide on practical issues such as different manufacturers of sheaths. This role of providing information conflicts with the formal BAC definition of a counsellor as someone who does not normally give advice (BAC, 1996a). The role of advice giving when it pertains to practical information may be helpful when working with people with SCI simply because of the lack of SCI knowledge within the community generally, even at the level of local hospitals and GP surgeries (Morris, 1989). At the same time, as also found by Oliver (1995), it was important that the counsellor did not treat people with SCI as a homogenous group but recognised that each client was their own expert in their condition. Max described how this places the client in the role of expert:

> 'Because also you're - you're giving your counsellee an opportunity to show that they know a little bit more, than you do or whatever. Give them a chance to empower themselves a little bit' (Max).

This is a difficult path for a counsellor to tread, but the helpful practitioners seen by Harry and Fred were able to achieve the balance between having knowledge whilst not being the expert within the relationship about the client's impairment.

Fred, Jane and Steve all gave examples of the negative body language they detected with their counsellor or psychologist which made them feel devalued in the counselling relationship. As discussed previously, the core conditions of empathy, congruence and acceptance underpin the quality of the therapeutic relationship and hence the effectiveness of the counselling. Therefore counsellors whose body language is cold and rejecting are unlikely to engage the client in productive counselling as this study confirms. Disabled people may be more adept than others at noticing incongruence in a counsellor because of their daily experiences in society of interacting with non-disabled people who do not hide their discomfort, or even revulsion about disabled people very well (Keith, 1996).

In contrast to this, Harry talked about the importance to him of the ways in which his last counsellor had used touch. She would touch his wrist occasionally and he found this enabled him to trust her so that he could talk more. This may have been a helpful way of counteracting the negative experiences he had whilst in the SIU when touch had meant exposure and invasive medical procedures – this was an example of 'good touch' (Oliver, 1995; 273). As Jane said:

> 'All these people who've been intruding into your physical - not just your physical space, but your body, somehow, you've got to get back, to owning your own body' (Jane).

It also appeared that the counsellor's touch validated Harry as a person and made him feel that the counsellor really cared about him. I acknowledge that there are issues around the use of touch within counselling relationships because it can be abusive (Bond, 2000). However I believe it would be valuable for future research to consider the use of 'appropriate' touch when working with disabled people because of the ways their bodies have often been objectified by the medical profession (Shakespeare et al., 1996).

Like Oliver (1995) I have shown that my participants want counselling that meets their needs and that this is not what current 'good practice' always provides. I believe that counsellors and agencies need to be more flexible in the way they provide their services (Reeve, 2000) and it may be time to reconsider some of the 'rules' which many counsellors follow, such as the refusal to do home visits (Nicholas, 1992) or use appropriate touch. I appreciate that these areas are a minefield laid with the highly charged issues of counsellor safety and the risk of allegations of counsellor abuse; however whilst these issues remain underground disabled people are not obtaining access to the services they need.

Training needs of counsellors

These suggested changes in counselling practice and theory need to run in parallel with improvements in counsellor training. I started out in Chapter One identifying the lack of Disability Equality Training on counselling courses and this problem has been highlighted in this study as well as by Lewis (1997) and Oliver (1995). DET, provided by a disabled person, would teach counsellors about the social model of disability and give them some insight into the levels of discrimination and social exclusion experienced by many disabled people (Withers, 1994). At the same time, this research has shown many examples of internalised oppression which were present within this small group of people with SCI. Whilst counsellors who have been taught basic DET would know what disability is, I do not think this training alone equips them with the insight needed to understand and expose the emotional effects of disability. Although they may not actively disable the client in the way that some of my participant's counsellors did, they would be unlikely to help the client recognise and resolve these internalised negative feelings.

I have been teaching DET on my local counselling course for several years and the course has recently achieved BAC accreditation. I am unusual in that I am a DET trainer *and* counsellor and so my training has always contained a section about some of the emotional effects of disablism; as a result I am teaching trainee counsellors about both the structural and psycho-emotional effects of disability. I believe that DET on counselling courses (for both disabled and non-disabled counsellors) needs to address both the structural and emotional aspects of disability more explicitly than is usual (e.g. as in Gillespie-Sells and Campbell, 1991). This training is also needed for counselling supervisors who oversee the work of counsellors. It would be useful to carry out a study that compared different DET courses and their contribution to counsellor effectiveness when working with disabled clients.

I have already discussed the fact that this study indicates that it is helpful if counsellors have knowledge about the client's impairment. A counselling course would not be expected to teach counsellors this information, although counsellors could access information themselves as and when needed from resources such as local organisations and the internet. I have reservations about encouraging counsellors to focus on the details of impairment in this manner because it could encourage the counsellor to view the client through the lens of the medical model and to adopt the role of the expert - although this was not the case in my study for the counsellors who had SCI knowledge. Another option would be the use of peer counsellors who do have personal experience of disability. SIUs make use of peer counselling and the SIA counselling service that uses counsellors with SCI is also a member of BAC. However the terms 'peer counselling' and 'peer support' are not clearly defined (Evans, 1993) and often the training given to these people is a short course in counselling *skills* which is quite different to training provided by a counselling Diploma. I would like to see research into how effective peer counsellors are when compared to counsellors with more formal training but no personal experience of disability.

Counselling training also needs to teach counsellors how to be more flexible in the ways they work with clients (Reeve, 2000). Alongside the provision of DET, I would like counselling courses to devote more time to reflexive practice, encouraging counsellors to identify their own prejudices about disabled people, or any other issue of difference such as culture (Lago and Thompson, 1996).

Summary

In this chapter I have shown how my participants want access to counselling which helps them take back control of their life and to move on. As the counsellor also needs to work within a social model definition of disability, I have suggested that people with SCI and other impairments might need a different counselling approach to non-disabled people for dealing with issues around impairment and disability; it is crucial that the counsellor understands the effects of disablism on people and has resolved their own issues about disability. My participants want access to a counsellor who knows about SCI and more research is needed to see how helpful specialist knowledge would be for other groups of disabled people, with acquired and congenital impairments. I have also suggested that DET which covers both the structural and psycho-emotional aspects of disability needs to be provided on counselling courses to educate counsellors about the effects of internalised oppression on disabled people.

I will now devote the next chapter to reflecting on my own research practice and discuss the issues that this raises for future counselling research.

Chapter 6

Emancipatory or Participatory Research?: Lessons for the future

This chapter will explore the extent to which my research could be considered emancipatory. I will also discuss the lessons I have learnt from the experience of undertaking this research. I will then build on these lessons to consider the applicability of emancipatory research for counselling research.

There have been many discussions about whether it is possible to achieve emancipatory research within our existing society without the existence of 'collective' research methods (Oliver, 1999) or fundamental changes in the material relations of research production (Zarb, 1992; 1997). I believe that it is still better to attempt to work towards emancipatory research than to give up on this methodology because of the lack of a collective research methodology or inclement political climate. Whilst my research did not challenge the material relations of research production directly, the fact that my MA dissertation was self-funded gave me some independence, limited only by the size of my bank account. I worked within the six principles of emancipatory disability research (Stone and Priestley, 1996) as far as was possible and I will now evaluate my research by considering the extent to which I achieved the three fundamental aims of emancipatory research – reciprocity, gain and empowerment (Oliver, 1992).

Reciprocity – reversing the social relations of research production

I decided to initiate this piece of research because of concerns resulting from my personal experience as a disabled client and counsellor – it was not initiated by an organisation of disabled people who then used my skills as a researcher as in other disability research (e.g. Priestley, 1997). However during the research I received validation of this research topic from both the SIA and my participants.

> 'But we've been through very unusual - but when I saw your thing, I - I thought, not only … but I looked at it, I thought we've got insights out of what came to us. It would help you help other people 'cos what happened to us, doesn't ever have to happen again, and people like you will stop it' (Pearl, Fred's wife).

So I feel that retrospectively some control of the research topic had been restored to disabled people and their organisations.

Given that disabled people are not a homogenous group (Mason, 1996) I am uncomfortable claiming epistemological privilege because I am disabled. Unlike some other disabled researchers (e.g. Swain and French, 1998), I do not see that being disabled myself automatically reverses the social relations of research production; the relationship between me and my participants is a social one and as such is subject to oppression at many levels such as class, gender, race and education in addition to disability. Instead I worked hard throughout the research process to reduce the risk of inadvertent oppression using supervision, self-analysis, a diary and personal counselling to resolve any issues I became aware of – and there were many! I also acknowledge that my research and interpretation has been subject to the time and academic constraints of an MA dissertation and that my accounts are affected by my intellectual and experiential biography (Thomas, 1999b; McLeod, 1996).

I tried to return as much control back to my participants as possible by involving them at all stages of the research process (see Chapter Three for more details). In reality this meant that they received a lot of information from me - most of the transcripts were more than thirty pages of standard print. I did not receive much feedback from participants apart from requests to change some small information details in several transcripts. On reflection I am left wondering if I may have been too demanding of my participant's time and attention by expecting them to validate transcripts and findings – in my attempts to ensure that I did not

oppress my participants by exploiting their experiences, I may have oppressed them with mounds of paper and information! I will need to address this dilemma for future research practice.

Another difficulty with reciprocity is how the researcher places their skills at the disposal of the research participants (Barnes, 1992) and the extent to which this is possible. Before starting the research I expected to be unable to put my skills at the disposal of the research participants, as I knew I could not offer any long-term counselling to people. Much to my surprise, I found I was able to offer information to participants - providing copies of videos to two participants and information for a third. I have also become friends with several of the participants (Vernon, 1997) which again was unexpected. I encouraged participants to contact me after the interview if they needed to discuss any issues further and this offer was accepted by one participant. The material which has been discussed subsequently has not formed part of the research project and I see this as one way of 'paying' someone back for the information and time they have given me (Skinner, 1998). In some ways reciprocity has been taken even further with participants 'helping' me; two participants have given me books and another person was able to give me some advice on a shared problem, something he felt very 'chuffed' to be able to do.

Who gained?

An important question is whether it is necessary for the research participants to benefit directly from the research, or whether research for the good of disabled people generally is sufficient (Stone and Priestley, 1996). When I started the research I predicted that it would benefit future disabled clients as a result of subsequent improvements to counselling practice, rather than my actual participants. Despite these reservations I hoped that the process of discussing a relationship which is naturally a private affair between counsellor and client would uncover and help resolve any difficult counselling experiences for participants. This did happen in the case of Fred and Pearl who found participating in the research beneficial and 'cathartic'.

> 'It's actually helping talking about this lady now. We've ignored it for years - it's just a horrible experience to have to be shut out, and move on, on to the next problem' (Pearl, Fred's wife).

This was the first time Fred had ever really talked about this counsellor and it helped them both realise how far they had come since that time and to put this experience to rest. Harry has started to realise how his shame and embarrassment at being a sexual man is linked to his past SIU experiences and this link is helping him make sense of these thoughts. I also gained enormously from being part of this research. It has been a valuable learning experience and I will take the lessons I learnt into future research practice. This research also contributes to my Masters degree and will be used to inform future publications and research.

How empowering was it?

At the end of the day the success of emancipatory research depends on the extent to which it has empowered disabled people (Oliver, 1997). Empowerment is not a gift which can be bestowed on someone – people can only empower themselves (Oliver, 1992). Two of my participants have now decided that they want to take part in research with other people, having gained confidence from being part of this research; one of these people is particularly interested in taking part in research related to the issues we discussed as he does not want anyone else to have to repeat the experiences he has had. Another participant recently raised a formal complaint against a professional for disablist behaviour which they felt they had only been aware of as a result of our interview discussions. I would consider that these participants have been actively empowered as a result of participating in this research. Whilst the experience of being listened to and valued as a research participant can be empowering (Vernon, 1997), I do not know the extent to which this empowered the other two participants. I also hope that I can use the results of this research to eventually improve the counselling experience, and hence self-empowerment of disabled people generally.

In conclusion I would describe this research as being more emancipatory than I expected, for me and my participants – it was not purely participatory research. I believe that a review of my research questions and methods might give rise to changes in the research process that would make future research more emancipatory.

Personal lessons

This attempt at emancipatory research has been a valuable opportunity to experience first-hand the sociological research process with all its reflexivity, doubts, fears and panic – very different from the scientific worlds of chemistry research and software development which formed the basis of my previous 'life' experience. I now want to discuss some of the personal lessons which this experience has taught me.

Like other qualitative researchers, I chose to study a topic which is personally significant and as a result I have been involved in much self-examination, personal learning and change (Grafanaki, 1996). However I underestimated the emotional affect of hearing about traumatic hospital experiences and oppressive counselling practice and had to work hard in the interviews to keep my issues and emotions to one side. I also experienced strong emotions when transcribing and analysing my results – again, these had to be worked through in my own counselling and in supervision. I learnt to be more flexible and to trust the process of my research, trying not to panic when my carefully laid plans had to be ditched and I was forced to think on my feet. Being a part of this research has changed me personally and professionally and was not a result I would have predicted beforehand; overall I believe these changes have been for the better!

Personal counselling supervision was crucial to my research process and I will always ensure that I have this form of personal support in any future research. I needed supervision for practical advice on issues such as how to prepare for an interview after the participant had revealed past childhood abuse. My supervisor helped set my interview boundaries with this participant in a way which was respectful and helpful for us both, which facilitated discussion of the issues I was interested in whilst at the same time respecting the importance of the disclosed information. I also needed supervision for my own personal benefit, as a safe place to untangle the emotional issues my participants were discussing from the responses they were creating in me. Like Skinner (1998), I agree that any sociological researcher who is dealing with sensitive issues, should have access to academic *and* counselling supervision to better understand the ways in which emotion and information are interlinked. I also believe that it offers more safeguards for the participant in such research and would like to see this included in the BSA Statement of Ethical Practice (BSA, 1993). It might also be appropriate to offer such researchers training in counselling skills so that they better understand the emotional aspects of sensitive issues such as abuse (Skinner, 1998).

I learnt many practical lessons from this research process. I was amazed at much time it took to organise just five interviews, arranging times, travel and accommodation. The cost of this project to me financially has been at least twice what I expected as I underestimated the cost of travelling to interview people in their homes. I discovered how much participants value and need confidentiality and several people commented how much safer they felt with a written confidentiality agreement (see Appendix 7). Whilst I already knew that confidentiality was important to people, by the end of the process I realised how vital it was for my participants to trust me about the way I was handling their information, and the personal responsibility which this placed on me. I was very relieved that I was not forced to break confidentiality by material disclosed by any of the participants.

I was very aware of the potential risks I took interviewing people in their own homes. By the time I visited people for the interview, I had already talked to them extensively by telephone or e-mail and felt safe visiting them. However I still took the precaution of leaving interview schedules and addresses with my partner as a security measure because I was very aware of being a female disabled researcher who would find it physically difficult to fend off an attack. As it happened, I had no problems with any of the people I visited who treated me very well. From this small study I have realised that some people prefer to talk on the telephone, and others prefer to talk face-to-face; in the interests of research that meets the needs of my

participants, I would like to offer both options again in the future whilst acknowledging the (small) risks to myself. I also experienced the effects that my presence as a female, disabled counsellor had on the interview process. I know that being disabled myself did help people feel more comfortable with me as they felt that I understood the issues they were talking about. On the other hand some of the difficulties I had when interviewing Max and Poppy were due to the fact that Poppy had a distrust of all counsellors – a problem I could not have predicted.

I have realised that that one of the potentially problematic areas of emancipatory research is the nature of the researcher-researched relationship. These relationships, which are more than open research relationships, place additional responsibilities on the researcher not to abuse those relationships as well as the need to be very aware of the risk of personal boundaries being breached. Even though I worked with these issues in my counselling supervision, I still struggled to maintain my boundaries as a disabled woman, counsellor *and* researcher. My counselling skills felt like a double-edged sword – they had the potential to facilitate exploration by the participant, but at the same time I had to remain vigilant that I did not expose people emotionally. I also had to listen to what people shared without being able to gently challenge assumptions and blind spots, in the way that I would naturally in a counselling situation (Etherington, 1996).

I also struggled with my boundaries as a disabled woman and researcher. Whilst I was happy to do everything I could to return control of the research process to my participants, I struggled with how to draw the line when asked questions about my personal life and impairment. I felt one person was overly intrusive with questions about my private life and personal comments about my body. As I was in their home to interview them, I felt it impossible to challenge the questions and comments. I felt very vulnerable and aware of my 'powerlessness' as a disabled woman. This struggle to maintain personal boundaries at the same time as giving back control to participants is one I will continue to engage with. It also suggests that doing emancipatory research can ironically lead to the abuse of the researcher, a reversal of the historical manner in which the researched have been abused (Oliver, 1992). This is an issue that would benefit from further discussion within disability studies.

Now that I have discussed the practical and personal experience of attempting emancipatory research, I will finally consider its application for future counselling research.

Emancipatory research as a paradigm for counselling research

Although emancipatory research has been attempted in disability studies (e.g. Vernon, 1997; Priestley, 1997) this is a new methodology for counselling research. As discussed in Chapter Two, counselling research is dominated by positivist research with a smattering of interpretive accounts. It has been predicted that interdisciplinary perspectives, appreciation of the power difference between researched and researcher, new methodologies and increased reflexivity on the part of the researcher will all have an important part to play in future counselling research (McLeod, 1994). The application of emancipatory research methodologies to this research project has been an important step in the right direction, building on the few recent attempts at participatory counselling research.

Many of the difficulties I encountered during this research have been experienced by researchers attempting participatory research in the counselling field. The most common problem is that of the dual role of researcher and counsellor with its associated dilemmas and boundary issues (Etherington 1996; Grafanaki, 1996; Hart and Crawford-Wright; 1999). It has been suggested that more research is needed to investigate the ways that counsellor training affects the nature of the research experience for both researcher and participant. It is noticeable that these attempts at participatory research have mainly involved building a 'working' alliance with participants – there has been little evidence of control being returned to the participant. Etherington (1996) offered all her participants a transcript of their interview tape and encouraged them to share their self-analysis on the contents with her. McLeod (1996) suggests that participants should be given a pre-publication copy of any findings so that they can verify the interpretations made by the researcher. In both cases there was no

suggestion that participants could control, rather than just verify, what was being used in the same manner that my research has attempted to do.

This reluctance to give back control to the research participants may not be unusual amongst counselling researchers. At the BAC Research Conference earlier this year I talked to an experienced researcher and writer about the emancipatory research I was planning to undertake. This person was horrified that I would allow my research participants to change the contents of interview transcripts and the suggestion that participants could withdraw at any stage of the research process caused him to gasp, "But then you would have no results!". However, for me personally, anti-oppressive behaviour towards my participants is far more important than having results to publish. Another challenge will be my stated rejection of 'objectivity' and the assumption may be made by other counselling researchers that my allegiance to the disabled people's movement means that I cannot hope to be 'objective' enough to produce rigorous research (Zarb, 1997); however oppression cannot be researched in an objective way (Oliver, 1997).

If emancipatory research is to become one of the new paradigms for future counselling research then more work is needed to lay down groundrules for undertaking this research. Because of the problems already discussed about the dual role of the researcher as counsellor, researchers will need more information, and maybe training, to avoid the pitfalls of this role. Supervision, whether individual or peer, is essential, providing a place where the researcher can separate out personal and professional responses, challenge assumptions and develop a better understanding of what the research process is producing (Etherington, 1996). Adequate supervision for researchers by supervisors with experience in research is already a research requirement included within BAC's Ethical Guidelines for Monitoring, Evaluation and Research in Counselling (BAC, 1996c). I also believe that the development of emancipatory research within counselling research will require additions to these ethical guidelines to provide guidance on the management of dual relationships and how to prevent research interviews turning into counselling sessions (Hart and Crawford-Wright, 1999).

I do believe that emancipatory research has a valuable part to play in counselling research, especially when researching the issues affecting oppressed groups within society. I consider that counselling, like social research is a political activity and this new methodology fits well with the newly emerging counselling theories which advocate an anti-oppression approach to counselling, confronting social oppression at all levels (McLeod, 1998). An emancipatory research approach may help to identify social oppression in the counsellor, counselling theories or institutions better than the traditional positivist or interpretive methodologies applied to date. However there needs to be more counselling research carried out using the emancipatory research paradigm before it will be accepted by the research community.

Summary

If the success of emancipatory research depends on the extent to which disabled people have been empowered, then I consider that this research has been emancipatory in many respects. I have discussed the problems I encountered trying to give back control to my participants at the same time as attempting to protect my own personal boundaries; I would like to see more discussion about the potential risks of abuse of the researcher in the effort to prevent abuse of the researched. I am sure that I will learn from the difficulties I experienced during this research to make any future research I undertake more emancipatory. Nonetheless I am firmly convinced that this level of reflexivity is a necessity when researching issues of oppression and is the reason why emancipatory research is something to be aimed for, even though it can be very stressful and hard work for the researcher.

Counselling research is currently debating the use of interdisciplinary methodologies such as participatory research and I have shown that it is possible to work within a research paradigm which gives back even more control to research participants. I believe that emancipatory research could offer a valuable way of looking at the counselling experiences of oppressed groups in society, but further study is needed to explore the implications that such research has on existing guidelines for ethical research. Emancipatory research, like the counselling

process itself, should be enabling, reflexive and self-critical (Barnes and Mercer, 1997); this new research methodology really does offer a:

> '… possibility of a growing convergence between research and practice in the field of counselling' (McLeod, 1996; 315)

and is worthy of consideration for future counselling research.

Chapter 7

Conclusion

This research set out to explore the ways in which people with SCI discussed issues around disability and impairment within counselling and to identify the ways in which the counsellor's views of disability and impairment affected the outcome of that counselling experience. My experience over the last six months whilst I have been doing this research has revealed many complex issues and has generated more questions than it answered. I will now summarise my findings from this research and offer suggestions for future research and discussion.

My choice of research methods together with my skills as a counsellor produced data that was rich and varied. At the same time as generating images of counselling relationships I was also given access to the private ways that people felt about their experiences of disability and impairment. I had not predicted the complex ways in which the practical and emotional aspects of disability and impairment would be interwoven and my analysis shows that it is not always possible to separate the impact and effects of one dimension from the other (Thomas, 1999a). Consequently disability and impairment cannot be simply mapped onto the familiar social/biological dualism and a better theoretical understanding needs to be developed within disability studies of the ways in which the different dimensions of disability and impairment interact.

Several of my participants talked frankly to their counsellors about the emotional effects of living with incontinence and the shame and embarrassment that this problem causes them. If the 'personal' experience of impairment is to be included within a social theory of disability (Oliver, 1996), then this theory needs to include *all* experiences of impairment, and not just the sociably acceptable experiences of fatigue and pain. My study has illustrated the significant effect that incontinence can have on the emotional well-being of a person and I consider it unacceptable to neglect this particular aspect of the personal experience of impairment any longer. I would suggest that further research into the emotional aspects of impairment effects would uncover other neglected areas.

My participants also talked to their counsellors about their experience of disability, the practical and emotional effects of living in a society that denigrates and excludes them. Some of the practitioners understood the ways in which society disables people and were able to counteract the internalised oppression of their clients; e.g. Harry's counsellor reassured him that his desires for a sexual relationship did not mean that he was a pervert. On the other hand, this research has shown the ways in which counselling can be an oppressive experience for people with SCI if the counsellor has a medical model view of disability and does not understand the physical and emotional implications of living in a disabling society. Even if the practitioner is not actively prejudiced, ignoring the impact of impairment and disability on someone's life can still be oppressive (e.g. as in Steve's case) because it is a denial of a disabled person's identity and reality. Counsellors and psychologists themselves are part of a disablist society and I have shown the ways in which their prejudices about disabled people can taint the counselling relationship, reinforcing the internalised oppression already present within the client. Although this research is based on a small sample, the fact that disability in one form or another is a common experience of disabled people as a whole suggests that this oppressive counselling experience may not be restricted to clients with SCI. More research is needed to explore the extent to which there is oppression in the counselling room when counsellors work with disabled clients (Reeve, 2000).

I have suggested that counsellors need to work with disabled clients within a counselling approach that recognises disability as a social construct if they are not to further disable their clients. Most of the counselling literature which deals with counselling disabled people is written within the definition of disability as individual tragedy, a 'loss' to be grieved before the person can 'accept' their disability. Although the 'loss' models were not used directly within the counselling experiences of my participants, the associated medical model view of disability was highly visible within some of the counsellors and psychologists discussed. This

disablist literature needs to be exposed and replaced with texts that discuss counselling within a social model context, such as work by Corker (1995) and Olkin (1999).

In addition to challenging the counselling literature, there are also implications for counsellor training. DET must become a recognised part of counsellor training, in the same way that other issues of 'difference' such as gender and race are. Whilst the provision of DET would educate counsellors about the differences between impairment and disability, this DET needs to be expanded to include the psycho-emotional aspects of disability, such as internalised oppression. Only then would counsellors be able to identify this aspect of disability within their disabled clients so that it could be worked with. More research is needed to look at the ways in which counsellors can work with internalised oppression in their clients and the training needed to achieve this.

I also discovered that my participants wanted a counselling approach which gave them 'space' to talk about their feelings but which also enabled them to take back control of their lives in practical ways. There was a general consensus that this group of people did not have the luxury of being able to 'navel-gaze' – they wanted practical solutions to everyday problems. More research is needed to explore whether a more directive form of counselling is wanted by other groups of disabled people; this poses the possibility that disabled people might want a different counselling approach to non-disabled people. In the same way that transcultural counselling has emerged to meet the needs of different cultural groups living in a racist society by recognising the issues of cultural difference, it might be appropriate to create a new counselling approach with the social model as a cornerstone or to adopt one of the newly emerging 'anti-oppression' approaches (Reeve, 2000).

Within my small sample, it was found that clients with SCI found it helpful to have a counsellor who had knowledge of SCI and its physical effects. This meant that the counsellor had some understanding of the implications of SCI and could provide practical advice on physical problems at the same time as not being:

> '… grossed out by the technicalities and the blood and the shit and the things everywhere' (Fred).

This particular suggestion challenges the traditional role of a counsellor as someone who does not give advice. It also reflects the lack of alternative sources of information about SCI available to these clients (Barnes, 1995). At the same time as wanting a counsellor who had 'knowledge', my participants felt it was important that the counsellor treated them as the expert about their impairment and did not make assumptions about how SCI affected them personally. Although a similar finding was made in a study involving people with MS, more research is needed to consider whether the counsellor always needs to have information about a disabled person's impairment in order to counsel them effectively.

All of my participants said they would return to counselling again in the future if they needed that form of emotional support. However the accessibility of counselling services needs to be improved if disabled people are to base their choice of counsellors on factors other than just how physically accessible they are. It was also stated that SIUs should provide counselling for all patients and that this counselling should be available when needed by self-referral. The use of appropriate touch within counselling was mentioned by one participant and I would like to see more research into this area when working with disabled people. My participants all reported bad experiences whilst they were patients within an SIU which were similar to the bad hospital experiences reported by many other disabled people; 'good' touch might offer one way of helping disabled people get back to owning their bodies. The psychological damage caused by SIUs also needs further investigation as my research showed these negative experiences are not just relics from the past. I also discovered that my participants did not have any preference for whether a counsellor was disabled or not, as long as that person had no unresolved issues about disability and met the criterion of working within the social model of disability.

I attempted to carry out this piece of research within the emancipatory paradigm and I consider that I succeeded in empowering three of my participants as a result of the research process. This research has also benefited me enormously, mainly from the experience of attempting this form of research, trying to give back as much control as possible to the

research participant. It has been hard work; the level of reflexivity and self-analysis required was more than I had expected. I have learnt many lessons from this experience; my main difficulties stemmed from maintaining my own boundaries at the same time as giving back control to the participant and I would like to see more discussion about the ways in which it is possible for the researcher, rather than the researched to be abused within the research relationship.

Despite the personal difficulties I encountered when working within this paradigm, I still believe it offers a way forward for future counselling research. Counselling research recognises that it has not addressed the issues faced by oppressed groups within society. The emancipatory research paradigm is about confronting social oppression and is therefore eminently suitable for undertaking research into the counselling experiences of these neglected groups of people. I recognise that there are methodological issues which will need to be resolved before emancipatory research is accepted; issues about the dual role of researcher and counsellor have already been raised by the recent attempts at participatory research. Even so, I feel that emancipatory research has much to offer counselling research and the time is now ripe to see further counselling studies carried out using this new methodology.

My study has identified many areas for further study in both the fields of counselling and disability studies. I firmly believe that with the improvements discussed previously, counselling could improve the emotional well-being of people with SCI as well as other groups of disabled people. I also acknowledge that counselling is focussed on providing individual solutions and as such does not challenge the social conditions that disable people in the first place. Nonetheless counselling has the potential to challenge internalised oppression and to help disabled people develop self-empowerment and a positive identity that will better enable them to claim their equal place in society.

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Appendix 1   Request for volunteers

Disability and Counselling

Over the last few years I have been pursuing two strands of interest – understanding what it means to be a disabled woman in society and training to be a counsellor. Whilst studying for the first year of the MA in Disability Studies at Leeds University these two strands have become well and truly knotted. The second year of this course involves a 9 month research project and I have decided to undertake a study of how disabled people experience counselling as part of an attempt to unravel these knots. I am hoping that some readers of FORWARD can help me with this task.

As most counselling training courses are not physically or financially accessible to disabled people, disability is not 'present in the room' in the same way that gender and race are. Counsellors receive equal opportunities training but disability is rarely included alongside the other areas of gender, sexuality and race. I was left wondering how counsellors trained under these conditions would work with disabled people, given that they had not had an opportunity to look at their own attitudes and prejudices about disabled people. Talking further to disabled friends convinced me that my concerns had some substance. Whilst some had experienced counsellors who had been very supportive and empowering, others had found their counsellor to be patronising and disablist and had abandoned counselling as having nothing positive to offer.

My research study will focus on the experiences of counselling from the perspective of the disabled person (as client), paying particular attention to the ways in which the counsellor was helpful or less helpful. I want to try and identify some of the factors that make a counselling relationship an empowering and positive experience, rather than a frustrating or ineffective one. As SIA provides a counselling service which some of you will have used, I hope to uncover differences in the experience of being counselled by a disabled counsellor rather than a non-disabled counsellor.

I am looking for any disabled members of SIA who would be willing to discuss their experiences of counselling with me. I plan to 'talk' to people in whatever way they feel most comfortable – telephone, in person, letter or e-mail. My expectations are that these discussions would take around an hour, depending on how much each individual wants to say. All information supplied to me will be handled in the strictest confidence and used anonymously in my final dissertation. I also intend to publish my findings in both FORWARD and a counselling journal. I hope that the results of this research study can be used to improve the training of counsellors so they can better serve disabled clients.

If you are a disabled member of SIA, have had experience of counselling and would like to be involved in research in this area, then please contact me for more information:

     Donna Reeve
     Redcot, St. James' Field, Pontypool, Gwent, South Wales NP4 6JT
     Tel: 01495 751034
     Fax: 01495 762386
     E-mail: donna@jarkwoman.co.uk

(In *Forward,* No. 36, March/April 2000*,* p. 3.)

Appendix 2 Background Information Questionnaire

This information will only be referred to in my final report to show the range of people taking part in this research and will be used anonymously.

You can either complete this questionnaire now and return it to me in the enclosed stamped addressed envelope or we can complete this questionnaire together at the start of the interview.

Here are five questions about yourself.

1. Name ……………………………………………………………….

2. Age now (Please circle one)
    Under 18   18-25   26-35   36-45   46-55   56-65   Over 65

3. Number of years since you became SCI (Please circle one)
    < 1 yr   1-2 yrs   3-5 yrs   6-10 yrs   11-20 yrs   21-30 yrs   > 30 yrs

4. Gender (Please circle one)
    Male   Female

5. Ethnic origin or descent (Please circle one)
    Indian   Black-Caribbean   Mixed Race
    Pakistani   Black-African   White-UK/Irish
    Bangladeshi   White European
    Chinese
    Asian – other   Black-other   White-other
    (please specify)   (please specify)   (please specify)

For the following questions about your counselling experiences please tick the appropriate box for each period of counselling, starting with the most recent in column 1, column 2 for the one before that etc.

If you have had more than 5 separate periods of counselling then please tick this box and answer the questions for the most recent five periods. ☐

6. How long ago did each period of counselling start?

	1	2	3	4	5
<1 year					
1-2 years					
3-5 years					
6-10 years					
11-20 years					
>20 years					

7. How long did each period of counselling last?

	1	2	3	4	5
<1 month					
1-2 months					
3-6 months					
7-12 months					
13-24 months s					
> 24 months					

8. Who suggested each period of counselling?

	1	2	3	4	5
Self					
Family					
Friend					
Professional					

9. How frequent were the counselling sessions for each of these periods of counselling?

	1	2	3	4	5
Daily					
Twice weekly					
Once weekly					
Fortnightly					
Monthly					
Less than monthly					
Varied					

10. Where did the counselling take place for each of these periods of counselling?

	1	2	3	4	5
Home visit					
Telephone					
Hospital - SIU					
Hospital - other					
GP Surgery					
Private counsellor					
Voluntary sector counsellor					
Other (please state)					

11. Who attended during each period of counselling?

	1	2	3	4	5
Only me					
Partner/friend also attended sometimes					
Partner/friend attended with me					
Other (please state)					

12. Was the counsellor you saw during any of these periods of counselling disabled themselves?

	1	2	3	4	5
Yes					
No					
Not sure					

13. Did you find each period of counselling helpful?

	1	2	3	4	5
Yes					
Somewhat					
No					
Not sure					

Thank you very much for filling in this form. Please send it back to me in the envelope provided.

Appendix 3   Information for research participants

About the researcher
My name is Donna Reeve and I have been a disabled person since birth. This research forms part of my Masters degree in Disability Studies being studied at Leeds University. I have experience of counselling as both a disabled counsellor and disabled client, and it is these experiences which have led me to look at the counselling experiences of disabled people.

About the research
The aim of this research is to look at how issues around disability and impairment are handled within a counselling relationship between counsellor and disabled client. How well does counselling work if the counsellor has a different idea of what disability means to you?

I have chosen to look at the particular experiences of people with SCI because of the potentially wide variety of counselling you may have been offered e.g. that provided by a SIU unit, GP practice, private counsellor or the SIA counselling service.

This research will attempt to give you as much control as possible over the research process by asking for any feedback you may care to offer at various stages. I will be offering you the chance to feedback at the following stages:
• On the Interview Topic Guide which describes what we will discuss in the interview.
• I am hoping to tape our interviews (with your permission) and I will transcribe the tapes shortly afterwards. You will be given the opportunity to check this transcript and to remove any material that you are unhappy about me using; sometimes people can say more in an interview than they mean to!
• I will send you a summary of my findings together with the supporting quotes I intend to use and would welcome any comments on my conclusions.

Your participation in this research is entirely voluntary and you are free to withdraw information or your participation at any time. If you do decide to withdraw from the process I would find it helpful to understand the reasons for this decision if possible.

It is also important that you are not currently seeing a counsellor, as participating in this research might adversely affect any on-going counselling relationship.

Confidentiality
The information that you provide to me will remain anonymous and confidential. However if I am provided with information which indicates that a third party is at risk of harm then I am bound by the British Association for Counselling Code of Ethics and Practice to take appropriate action after consultation with you and my counselling supervisor.

I will take the following steps to ensure confidentiality:
• Your personal details such as name, address are kept in a separate locked file away from the rest of the research material.
• The information from the Background Information Questionnaire will be collated anonymously and the paper questionnaires destroyed.
• Interview transcriptions will use the pseudonym you have chosen and any identifying material such as SIU, counsellor name etc., will be changed.
• Once the interview has been transcribed, the tape will be destroyed.
• Any discussions with my supervisors will retain your anonymity.

Supervision
As this research project crosses both sociology and counselling I have supervision for this research project from two sources. My two tutors, Dr Colin Barnes and Dr Geof Mercer in the Sociology and Social Policy department at Leeds University, are available to offer support for practical and theoretical issues arising from the research. I also have supervision with a counselling supervisor who will give me personal support during the interview process, in much the same way as a counsellor is supported when seeing clients.

Estimated time-scales for project
• April 2000 – Publication of request for volunteers in *Forward* magazine.

- May 2000 – Send out information to participants, receive voluntary feedback on Interview Topic Guide and schedule interviews.
- End May - June 2000 – Carry out interviews and transcribe tapes.
- End June – mid July 2000 – Send out interview transcripts to participants for optional feedback.
- Start August 2000 – Send out summary report to participants for optional feedback.
- 1st September 2000 – MA dissertation complete.

<u>Use of collected data</u>
The information collected during this research will be used as part of my MA dissertation that will be placed in Leeds University library for access by other students. I plan to produce a report of my findings for SIA and a short article for *Forward*. Information collected may also be used to write articles for disability and counselling journals such *as Disability & Society* and *Counselling*.

As information you give to me may be used anonymously to produce 'public' documents, you may want to remember this fact when reviewing the interview transcripts, removing anything that would make you feel uncomfortable if you came across it later in something I had written.

<u>My contact information</u>
Name: Donna Reeve
Address: Redcot
            St. James' Field
            Pontypool
            Gwent
            NP4 6JT
Telephone: 01495 751034
Fax: 01495 762386
E-mail: donna@jarkwoman.co.uk

Appendix 4   Draft Interview Topic Guide

For each separate period of counselling that you have had please think back to how (if at all) you explored the following three areas with your counsellor:

1. Talking about impairment
- Did you talk about any issues related to your impairment e.g. pain, medical issues?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel believed ? Did it help?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

2. Talking about disability
- Did you talk about any issues relating to disability – things that you cannot do because of other people's attitudes or physical barriers e.g. visit friend's houses?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel believed? Did it help? Was impairment seen as the reason for disability?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

3. Talking about how you feel about yourself as a disabled person
- Did you talk about any issues relating to how you feel about yourself as a disabled person e.g. self-worth, sexuality?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel understood and valued? Did it help?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

For each separate period of counselling that you have had please think back to the counselling experience generally:

4. The counselling experience
• Did you feel that you had to educate the counsellor?
• Was the counsellor able to see things from your point of view, as a disabled person living in society?
• How did the prejudices and attitudes of the counsellor towards you change over the time you worked together (if at all)?
• How was the experience of being counselled by another disabled person? (if relevant)
• How was the experience of being counselled by a non-disabled person? (if relevant)
• What role did the counsellor adopt towards you – ally, neutral, advocate, friend, professional?
• Was it a helpful experience, one you would repeat? In what ways did it help your feelings towards impairment, disability and how you feel about yourself as a disabled person?
• What, if anything, would have made the experience more positive for you? (E.g. training for counsellors, different counselling venue etc.)

Appendix 5   Feedback Comments on Interview Topic Guide

Once you have had a chance to look at the areas I am interested in talking to you about, I would be very pleased to receive any feedback you may have on the proposed topics. For example you may think that I have missed out some important areas you would like to talk about.

If you do not wish to make any comments then please return the blank form to me. Otherwise please tick the appropriate boxes and provide more information where appropriate.

Name ………………………………….

1. Talking about impairment

☐   I am happy to discuss the proposed questions in this area

☐   I would like to discuss this further with you by phone

☐   I would like to discuss this further with you by e-mail

☐   I would like to suggest the following changes:

2. Talking about disability

☐   I am happy to discuss the proposed questions in this area

☐   I would like to discuss this further with you by phone

☐   I would like to discuss this further with you by e-mail

☐   I would like to suggest the following changes:

3. Talking about how you feel about yourself as a disabled person

☐   I am happy to discuss the proposed questions in this area

☐   I would like to discuss this further with you by phone

☐   I would like to discuss this further with you by e-mail

☐   I would like to suggest the following changes:

Interview Topic Feedback Form
Donna Reeve   (01495 751034)

4. The counselling experience

☐   I am happy to discuss the proposed questions in this area

☐   I would like to discuss this further with you by phone

☐   I would like to discuss this further with you by e-mail

☐   I would like to suggest the following changes:

Any general comments

Thank you very much for filling in this form. Please send it back to me in the envelope provided.

Appendix 6   Interview Information Questionnaire

Please could you provide me with information to help me start scheduling and organising the interviews, which should take place between the end of May and during June 2000. I will draw up a rough schedule and then contact each of you by phone and confirm when it would be most convenient to visit or telephone.

1. Name ……………………………………………………………….

2. How would you like to be interviewed? (please circle one)

   Face-to-face interview   By telephone   Either   Not sure

3. Would you be willing to allow me to tape our interview? This would provide me with an accurate and rich source of information for the project. (Please circle one)

   Yes   No   Not sure

4. Which days of the week are most suitable for us to talk? (please circle)

   Monday   Tuesday   Wednesday   Thursday   Friday
   Saturday   Sunday

5. Which times of day are most suitable for us to talk? (please circle)

   Morning   Afternoon   Evening

6. Please give details of any dates that are not available for us to talk e.g. holidays.

7. When I transcribe the interviews I will use a pseudonym to protect your identity such as Mary or Peter. What name would you like me to use in my research?
   Name ……………………………………

Thank you very much for filling in this form. Please send it back to me in the envelope provided.

Appendix 7   Consent Form

It is important that you feel fully informed about this research before agreeing to take part. If you have further questions then please contact me and I will provide the necessary information. If you have read the enclosed information with this form and feel happy to proceed then please sign this consent form.

As a participant in this research, you can expect the following things from me:

- The information you provide me with will remain anonymous and confidential at all times (unless there is risk of harm to a third party as described in the Information material).
- The opportunity to provide any comments/feedback that you wish to make on the areas to be discussed during the interview as well as on the conclusions I make from the information I collect.
- The opportunity to check and approve interview transcripts before they are used in the dissertation.
- **Your participation in this research is entirely voluntary and you are free to withdraw information or your participation at any time.**
- If at anytime you are unhappy with me as a researcher or with the research I am doing then please contact me on 01495 751034 and I will do my best to resolve the problem.

I agree to participate in this research and understand that I am free to withdraw any information, or my participation, at any time. I am not currently seeing a counsellor.

……………… ………………………………………… Date …………

Donna Reeve   ………………………………………… Date …………

This research is supervised by Dr Colin Barnes and Dr Geof Mercer, School of Sociology & Social Policy, University of Leeds, Leeds LS2 9JT.

Please sign both copies of this consent form and return the yellow copy to me in the enclosed envelope.

Consent Form
Donna Reeve   (01495 751034)

Appendix 8   Interview Topic Guide – Final Version

For each separate period of counselling that you have had please think back to how (if at all) you explored the following three areas with your counsellor:

1. Talking about impairment
- Did you talk about any issues related to your impairment e.g. pain, medical issues?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel believed? Did it help?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

2. Talking about disability
- Did you talk about any issues relating to disability – things that you cannot do because of other people's attitudes or physical barriers e.g. visit friend's houses?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel believed? Did it help? Was impairment seen as the reason for disability?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

3. Talking about how you feel about yourself as a disabled person
- Did you talk about any issues relating to how you feel about yourself as a disabled person e.g. self-worth, sexuality?
- If so, how did the counsellor handle this? What were their responses? Did you feel supported? Did you feel understood and valued? Did it help?
- If you did not talk about this – was it because you chose not to? Not safe? Not an issue?
- Were there issues that you felt uncomfortable talking about? Why? What would have made it easier?

For each separate period of counselling that you have had please think back to the counselling experience generally:

4. The counselling experience
• Did you feel that you had to educate the counsellor?
• Was the counsellor able to see things from your point of view, as a disabled person living in society?
• How did the prejudices and attitudes of the counsellor towards you change over the time you worked together (if at all)?
• How did the fact that your counsellor was disabled or non-disabled affect this counselling experience?
• Was it a helpful experience, one you would repeat? In what ways did it help your feelings towards impairment, disability and how you feel about yourself as a disabled person?
• What, if anything, would have made the experience more positive for you? (E.g. training for counsellors, different counselling venue etc.)

Appendix 9   Information about the interview

Following your feedback comments on the Interview Topic Guide I have made some changes to the section called "The counselling experience". The changes are small and can be found in the copy of the "Interview Topic Guide – Final Version" enclosed with this package. I will be using this version of the topic guide for our interview.

My suggestion for the interview format is that we discuss the four subject areas of interest that I outlined in the Interview Topic Guide for each period of counselling in turn. For example, if you saw two different counsellors, then we would discuss how issues around impairment, disability and identity were handled as well as how the counselling experience felt for one counsellor, before moving on to discussing the same areas for the second counselling experience.

As we discuss each of the four subject areas, I will leave it to you to talk about the area in whatever way feels most comfortable. I am willing to ask you the individual questions for each area if you wish, or to refer to them only if you become "stuck". I will go through the questions before we start the interview to refresh your memory, if that would be useful.

These are just suggestions for how we can do the interview - if you would feel happier tackling the interview in a different way then we can talk about this when we meet or you can call me beforehand.

This package also contains information about things you might need to say during the interview and how I will respond to you, e.g. if you do not want to say anymore about a particular subject.

I will not start the interview until you are comfortable and happy with what we plan to do.

Appendix 10   Things you might want to say

I want this interview to be as comfortable as possible for you. It is important that you only talk about things you feel happy sharing with me and have complete control over how much you say. Here is a list of the kind of concerns you might have during our interview, together with my response if these arise:

"I don't understand the question/subject"
"Why do you want me to talk about this subject?"
I will try and explain further.

"I don't know what to say about this subject"
I will ask some of the questions from that subject area in the topic guide to see if this brings anything to your mind.

"I do not want to answer this question"
"I do not want to say any more about this subject"
I will move onto the next question or subject. You do not need to explain why.

"I would like to come back to this question/subject later"
I will make a note to return and move onto the next question/subject.

"I do not want you to tape this part of the interview"
I will turn off the tape until you are happy for me to resume taping.

"I would like to stop for a break"
I will stop for whatever time you need.

If you have any other concerns about the interview, then we can talk about these before, or during the interview. I will do everything I can to make the interview as easy as possible for you.

Appendix 11   Further information

Accessing a counsellor
SIA (Spinal Injuries Association) offer a free telephone counselling service that is provided by counsellors with SCI. They can be contacted on 020 8883 4296.

Many GP practices offer free counselling to patients although this is often limited to a certain number of sessions.

The British Association for Counselling (BAC) maintains a United Kingdom Register of Counsellors. The counsellors on this list are appropriately qualified, work to Codes of Ethics and Practice and are subject to Complaints Procedures. You can find details of counsellors in your area by contacting BAC on
Tel: 01788 568739   Fax: 01788 546809
E-mail: alanl@bac.co.uk or helen@bac.co.uk
This counselling usually costs about £20 or more per session.

You may also find other sources of counselling in Yellow Pages, under "Counselling and Advice".

Further reading
Morris, J. (ed.) (1989) *Able Lives: Women's experience of paralysis.* London: Women's Press. Very readable book which includes the psychological accounts of women with SCI.
Oliver, M., Zarb, G., Moore, M., Silver, J. and Salisbury, V. (1988) *Walking into Darkness: the Experience of Spinal Injury.* London: Macmillan.
At least one chapter in this book deals with psychological effects. Out of print now, but you can get it through inter-library loan. Very readable.
Trieschmann, R. (1988) *Spinal Cord Injuries: Psychological, Social and Vocational Rehabilitation (2nd Edn.).* New York: Demos.
An American book which I have yet to read.
Lenny, J. (1993) 'Do disabled people need counselling?', in J. Swain, V. Finkelstein, S. French and M. Oliver (eds.) *Disabling Barriers – Enabling Environments.* London: Sage and Open University Press.
This chapter criticises some of the assumptions that counselling makes about becoming disabled as raised by disabled people themselves.

Appendix 12   Feedback Comments on Transcript

This is your chance to make any changes to the material we discussed during our recent interview. I have used your pseudonym throughout and have made other identifying information as anonymous as possible.

Please read through it and let me know if you want to change or remove anything. You can mark up the copy you have of the transcript before returning it to me, or we can go through the changes by e-mail or telephone. You can keep the transcript if it does not need to be returned to me with changes.

If you do not wish to make any comments then please return the blank form to me. Otherwise please tick the appropriate boxes and provide more information where appropriate.

Name   «Pseudonym»

☐   I am happy with the contents of the transcript

☐   I enclose an amended version of the transcript

☐   I would like to discuss this further with you by phone

☐   I would like to discuss this further with you by e-mail

☐   I would like to suggest the following changes:

Thank you very much for filling in this form. Please send it back to me in the envelope provided.

Transcript Feedback Form
Donna Reeve   (01495 751034)

Appendix 13 Coding categories

1. General Counselling Issues:
• Body language
• Physical access to counsellor and counselling premises
• Relationship nature e.g. friendly, distant
• Confidentiality Issues
• Experience/knowledge of SCI
• Counselling approach used
• General counsellor ability
• Presenting issues when started counselling
• Returning to counselling in the future

2. Impairment Issues:
• Assumptions held by counsellor about impairment
• Information about impairment provided by client to the counsellor
• Impairment discussed e.g. incontinence, paralysis
• Helpful responses by counsellor when impairment discussed
• Unhelpful responses by counsellor when impairment discussed
• Psycho-emotional effects of impairment discussed e.g. embarrassment around incontinence
• Helpful responses by counsellor when psycho-emotional effects of impairment discussed
• Unhelpful responses by counsellor when psycho-emotional effects of impairment discussed
• Attitude of client to impairment

3. Disability Issues:
• Assumptions held by counsellor about disability
• Information about disability provided by client to the counsellor
• Disability discussed e.g. lack of access to buildings
• Helpful responses by counsellor when disability discussed
• Unhelpful responses by counsellor when disability discussed
• Psycho-emotional effects of disability discussed e.g. lack of self-worth
• Helpful responses by counsellor when psycho-emotional effects of disability discussed
• Unhelpful responses by counsellor when psycho-emotional effects of disability discussed
• Attitude of client to disability

4. Disabled and non-disabled counsellors:
• General problems with counsellors
• Disabled vs. non-disabled counsellors

5. Future improvements for counselling:
• Handling of impairment issues by counsellors
• Handling of disability issues by counsellors
• Access to counselling services
• Training
• Requirements of individual counsellors
• Counselling approaches

6. Other issues:
• SIU/Hospital experiences
• Other issues discussed e.g. family problems
• Questions and comments directed at me personally
• My verbalised concerns which came up during an interview

Appendix 14   Draft summary of findings

Talking about impairment
All of the research participants had first entered counselling because of an impairment-related issue. Generally this was in response to becoming SCI (about 1-2 years after the event) or following a deterioration in their condition. For two of these people, the initial counselling experience was so bad that they did not try counselling again for many more years.

Incontinence was a subject discussed by three out of five of the participants with their counsellors and was handled in differing ways.

One counsellor did not want to hear about impairment and attributed all the couple's problems to marriage failures, ignoring the impact that impairment was having on both people. The counsellor appeared to be unable to cope with hearing about these difficulties.

> 'I was having trouble coping with Fred being incontinent. Fred was having trouble coping with Fred being incontinent, and if we talked about that she said that you have to listen to each other. Huh, I don't want to fucking listen to him, I want to not have to get up in the night to empty a pee bag – I'm tired, I'm sleepy.' (Pearl, Fred's partner)

In contrast some counsellors were very supportive and offered information and advice about product sources – they were knowledgeable about SCI and its related physical problems.

> (As a result Harry was able to change to a different brand of sheath which caused him less problems and made life more comfortable.)

One participant wanted space to talk about how she felt about her increased impairment following botched abdominal surgery and osteomyelitis. Rather than listening, the counsellor insisted that this person needed a second opinion from another doctor. The counsellor also promised to find out more information about osteomyelitis, which he failed to do. This reinforced the message

which the participant had already received from hospital – that there is no space for you if you can't be cured.

> 'And all I wanted, and I – I, was somebody to say - to listen to me and say "Yes, you're right to be angry", but allow me to go through - I mean I understand it now better than I did then but I think all I wanted was somebody who wasn't going to get fed up with me talking for a few, for a few sessions until I could just settle down to the fact that actually yes, that had all happened to me, nobody was going to tell me that it hadn't happened and that when I was ready to then move on - I could move on. But he, he wasn't wise enough or knowledgeable enough to understand that sometimes that's all people want, they don't want, there isn't a cure. … ' (Jane)

> ' that there's no space for you if there's no cure, sort of thing - you know, that, that they didn't want you in hospital because there was nothing more they could do …
> they only had time for people who actually they could do something about. … I was searching desperately for just somebody to have time for me - nobody had time - and that was what I was looking for in the counselling session' (Jane).

Apart from talking about the practicalities of impairment, people also talked about the emotional effects of impairment. The most common thread was about the embarrassment and humiliation felt around the issue of incontinence.

Generally it was felt that the counsellor was able to understand these feelings in the cases where people felt comfortable discussing the issue in the first place. However only three of the counsellors were able to help the person actively resolve their embarrassment and reduce the emotional consequences of future 'accidents'. One way was a 'reassurance' that they were not the only person to experience this, which was found to be helpful. It also helped having somebody acknowledge the emotional effects of incontinence, the humiliation, at the same time as allowing it to be talked about as a practical issue.

> Fred: On one visit I pissed myself in the car on the way up and I tried to change my sheath and saw piss flying everywhere around the car, I was really pissed off as you can imagine, and er I was saying to [the psychologist], "I feel

> really dirty and pissed off about this" and he says "Bugger me - I thought it was part of spinal injury" and then he say …
>
> Pearl: ….. he said he have to go and tell the other patients - all his patients - they weren't spinal injured, just stupid and they could pull themselves together and get over it!
>
> 'not grossed out by the technicalities and the blood and the shit and the things everywhere ' (Fred)

Another participant became frustrated when talking about the fact that painful spasms made touch, and hence relationships, difficult. His psychologist ignored this fact and instead interpreted his reluctance for touch as being a psychological problem with roots in his childhood.

> 'And I don't want people to grab me, because that gives me a spasm. And a spasm, a spasm can throw me out the chair. So you get to the stage after a while where, you don't – it's not as though you don't want to be touched, there is an implication that touching – and it's bad news. It's not good from a relationship point of view, but it's a fact of my life – I can't get away from that. …. Um, if she'd [the first counsellor] understood the disability aspect of it, she would have understood why, that happened. But she didn't, she says "Alright, I'm a psychologist, so therefore people who don't like being touched, there's got to be some deep-seated psychological reason"' (Steve).

Summary – impairment was something everybody talked about to their counsellor. It needed to be acknowledged as an issue and practical solutions to practical problems were welcomed. People needed the counsellor to be able to hear what they said, but to help keep the problem in perspective, especially with subjects like incontinence, which are social taboos. Counsellors and psychologists who interpreted what was being said - needing a cure, or due to relationship problems – were not helpful.

Talking about disability
Only one participant initially started counselling to talk about disability issues although four participants did end up talking about disability at some point.

One counsellor refused to discuss disability in any form; disability related issues such as social exclusion were interpreted as evidence of marriage problems.

> ,the "colossal social pressure [for Pearl] to conform and be a martyr and look after Fred" (Pearl, Fred's partner)

Her "coercive" and condescending attitude extended to the manner in which she grudgingly admitted the participant into her house, as he had to be carried in because of steps at the entrance.

> This made Fred
> 'feel like shit. Here I'm supposed to be being helped, and I am just being made to feel more in the way … [she] spoke mainly to Pearl… it was very much "Does he take sugar" thing, and from a counsellor which was, not good - no. We haven't seen her anymore, funny enough'. (Fred)

One counsellor failed to appreciate the frustration and effort that living in an inaccessible environment caused, together with the fact that this was an everyday experience for their client. This counsellor also failed to understand the importance of maintaining personal independence and appeared to view disabled people as passive recipients of care.

> 'And she couldn't understand why I would do that. Why don't I just say, get somebody to do it for me? Well, I said "Well, you know, why do you get out of bed in the morning?". It's – it was as though the attitude was, well if you're disabled, sit there and provided you're warm, dry and fed, what more do you want?' (Steve)

A final counsellor (in the 1960's) denied one participant the opportunity to talk about sex or girls and as a result he was made to feel guilty about wanting a sexual relationship with a woman. For the next 30 years he felt shame and humiliation, believing that he was a 'pervert'.

> "Oh, you've got enough to think about, you know", um, um, without thinking about that. I said, "Well, sex is important to me". She – good Lord – she said, "You'll probably find, you'll bump into a disabled girl sooner or later". (Harry)

(When Harry left his SIU he felt unattractive physically and had become very self-conscious about his body due to experiences whilst in hospital.)

It was not until 30 years later that this participant found, by accident, a disabled counsellor who had SCI who was able to reassure this person that he was like any other man, and <u>definitely</u> not a pervert. As a result he stopped feeling ashamed and was able to experience sexual relationships with women.

"I haven't known a man who doesn't think like you. So you're not – there's nothing perverted, nothing" (Counsellor to Harry).

Incidentally all participants talked about hospital/SIU experiences and the ways in which they had ended up feeling embarrassed, humiliated and ashamed of themselves, usually because of the way they were treated by the medical profession. These experiences spanned the 1960s to the early 1990s and cannot be ignored and put down to out-of-date practices – it is still happening today.

<u>Summary</u>: Counsellors who had experience of other disabled people or knowledge of SCI were much more able to help people work with how they felt about disability. Counsellors who did not have knowledge of SCI or experience of disability were more likely to make clients with SCI feel worse about themselves as disabled people.

Discussion about counselling people with SCI
There was no clear answer as to whether psychologists were better at helping people with SCI than counsellors. It would appear that the approach (i.e. how flexible they were) taken by the person and their knowledge of SCI was a far better indicator of how good they were, rather than their professional qualifications. It is also possible that some of the counsellors and psychologists were not very good at counselling anyway – nothing to do with the fact that the client had SCI.

Grief models which describe a person's response to disability were not widely used by the counsellors or psychologists discussed in this study. One participant found the suggestion that 'losing his

legs' was a loss to be grieved, was an interesting idea. One psychologist suggested that grieving could occur over the loss of the pre-injury person although the participant did not find this a particularly helpful concept.

The body language of counsellors was commented upon by several participants. Counsellors who appeared aloof and detached were found to be unhelpful and even damaged the counsellor-client relationship by making the client feel that the counsellor did not want to work with them. By comparison one person commented how much they had appreciated gentle touch (a hand on the wrist) as a way of communicating that the counsellor cared and wanted to help.

Lack of access to counselling premises caused difficulties for several participants. In each case it was handled with a lack of respect for the disabled client who was made to feel 'different' and 'in the way'. If the client detected negative attitudes such as these from the counsellor, then the quality and outcome of the counselling was adversely affected. Finally in one case, the counsellor was also a friend of the client; this created problems because the boundaries between friendship and counselling were blurred. The main reason why this situation had arisen was because the participant was not offered counselling by his SIU and he needed to talk to someone about how he was feeling.

When counselling is done well it can help people cope better with things like incontinence and to feel better about themselves as disabled people – if done badly, it makes things worse and can be oppressive. All my participants did take impairment and disability issues to counselling, but they were dealt with successfully by only 4 out of 10 counsellors/psychologists, all four had extensive knowledge of SCI (2 worked within an SIU, one had SCI, one had worked with a lot of people with SCI). Whilst not a large sample, this is significant enough to suggest a link between effectiveness and SCI knowledge. The other counsellors/psychologists (6) had a lack of understanding about the practicalities of living with SCI and as a result, at best they were supportive but unable to help people move on, at worst they often misinterpreted what they were told and were oppressive.

Two of the counsellors were disabled in this study. Whilst disabled counsellors may have more shared experience with the client and

therefore more empathy, this is negated if they have a medical model view of disability, or have not sorted out their own issues about being disabled.

> 'Um, 'cos you know -you as a counsellor - a disabled counsellor being disabled yourself, you might be having some really big chips on your shoulder anyhow, and instead of helping this newly disabled person, you're sort of verbally giving them your chips on your shoulder – "Do have a plateful of my chips!" '(Poppy, Max's partner)

The potential benefit of shared experience present with a disabled counsellor was considered to be less important than the requirement that the counsellor has no emotional baggage of their own.

Summary: The most helpful counsellors/psychologists adopted a positive attitude to their client and understood the issues about SCI and disability; as a result their clients felt better able to deal emotionally with impairment problems such as incontinence, felt more positive about themselves and were enabled to make positive changes in their lives. Conversely, those counsellors who had no knowledge of SCI were at best supportive, or at worst oppressive, making their clients feel worse about themselves. Counsellors can be disabled or non-disabled, so long as they have no emotional baggage about impairment or disability.

Future directions for counselling
People want counselling to provide a space where they can dump their feelings about impairment, without judgement or horrifying the counsellor. They then want help to move on, to find solutions to problems. It could be suggested that a problem-focussed style of counselling may be more beneficial for people with SCI than a person-centred approach in which the counsellor is completely non-directive.

> 'And I think that's maybe what - what somebody should have - should have said back, and took me away from this concentration on impairment and actually challenged me to say well "That's what - that that's a fact. All those horrible things that happened to you" - had - had - had you - if I had - if somebody had come at me with a social model to try and

> move me away from getting blocked in to that medical …'
> (Jane)
>
> 'But there, but if there was a counsellor there for him that
> could do this with him, that says, "This pisses you off to piss
> yourself dunnit", somebody that's quite happy to do that,
> something that will hit it, you know, on like that …' (Poppy,
> Max's partner)
>
> 'And one thing that doesn't work, is this "give people space"
> business. There has to be some direction to it, cos - what
> was it [the psychologist] said -"The general idea is to get you
> back to normal life, or at least normal for you", so that you
> can't - nobody can afford two years clambering around in a
> morass of upset feelings. Somebody has to say "This is the
> way out of this one - it's worked for other people - if it doesn't
> work for you, we'll find another path, but this is the way most
> people find helpful"… ' (Pearl, Fred's partner)

Counsellors working with people with SCI need to be flexible and
to work in the way that most helps their client. This may entail
offering appropriate use of touch – I suggest that this might
validate people and help counteract some of the negative physical
experiences in hospital involving invasive procedures affecting the
body.

> 'All these people who've been intruding into your physical -
> not just your physical space, but your body, somehow,
> you've got to get back, to owning your own body.' (Jane)

Counselling needs to be available when required (and not just after
injury) through self-referral. SIUs need to offer counselling to all
people, and not just to those who appear to need it. On a separate
note SIUs need to assess the way they treat their patients so that
they are not emotionally damaged during their stay in hospital.
> (Jane – not wanted in hospital if they couldn't cure you)
> 'They were just rolling bags of bones, and clean the shit off
> the bag of bones - they weren't dealing with people. It is one
> of the most humiliating environments I have ever seen'
> (Pearl, Fred's partner)
> (Harry – being exposed and left naked by hospital staff.)

Counsellors need to know more about SCI and its effects. Sometimes counsellors need to be able to provide information to clients (which is not regarded as a usual counsellor role), although at the same time it is important they still regard the client as the expert with respect to their experience of impairment and disability.

> 'Because also you're - you're giving your counsellee an opportunity to show that they know a little bit more, than you do or whatever. Give them a chance to empower themselves a little bit.' (Max)

Counselling needs to be accessible to people – not just available by phone. Counselling services need to have accessible rooms and the problems with accessible public transport have to be taken into account.

> 'Oh, yes. Locally as well, they shouldn't have to sort of speak to somebody in London, or – they should, I mean … I don't know whether Relate, I mean, they say they counsel disabled - but I don't know, but um. I just know, well you see I mean, our – my - our nearest Relate is in [town] which is, say fifteen miles away. But I mean, you've got to get over there and back which is not easy. I can't use public transport, I don't drive anymore now, so um, how do you get over there? They don't even have taxis which takes a wheelchair 'round here, you see, so you're – so I mean that's another problem.' (Harry)

There are impacts on counsellor training arising from this study. Basic Disability Equality Training is probably not sufficient for counsellors working with clients with SCI – they also need to have access to information about SCI and to understand the frustrations and emotional aspects of being a disabled person within our society. Counsellors also need access to good supervision with supervisors who are also trained in these areas.

Summary: Counselling which offers a more problem-solving approach may be more helpful than a person-centred approach in helping clients move on and get on with their lives. Counselling should be available to all people with SCI throughout their lives and not just at the time of injury. Counselling services need to be fully accessible to this client group so that people can choose whether to use a telephone service (such as SIA in London) or a

local face-to-face service. Counsellor training needs to be improved to include more than basic Disability Equality Training – counsellors also need to understand the emotional experience of being disabled within society and to have access to information about SCI and its associated physical problems.

Additional quotes being used in other parts of the dissertation

How beneficial was the research for participants:

> 'It's actually helping talking about this lady now. We've ignored it for years - it's just a horrible experience to have to be shut out, and move on, on to the next problem.' (Pearl, Fred's partner)

(In fact Fred talked about this counsellor in ways he had never before, which Pearl appreciated hearing and understanding; it helped them both realise how far they had come since that time and to put this experience to rest. Talking to me also helped them identify disablist attitudes in another professional and they were able to raise an official complaint about the way this person had treated them.)

Validation of the research topic:

> 'But we've been through very unusual - but when I saw your thing, I - I thought, not only … but I looked at it, I thought we've got insights out of what came to us. It would help you help other people 'cos what happened to us, doesn't ever have to happen again, and people like you will stop it.' (Pearl, Fred's partner)

Appendix 15   Feedback Comments on Draft Summary of Findings

This is your chance to comment on my findings as presented in the accompanying document. You can also change or remove any of the quotes or personal information that I have used if you want.

Please read through it and let me know if you want to change or remove any of the quotes or personal information. You can mark up the copy you have of the summary before returning it to me, or we can go through the changes by e-mail or telephone. You can keep the summary if it does not need to be returned to me with changes.

If you do not wish to make any comments then please return the blank form to me. Otherwise please tick the appropriate boxes and provide more information where appropriate.

Name   «Pseudonym»

☐   I am happy with the contents of the summary

☐   I enclose an amended version of the summary

☐   I would like to discuss this further with you by phone

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☐   I would like to suggest the following comments on your findings: