

**Living with multiple sclerosis :  
women's experiences of sexuality  
and intimate relationships**

**by**

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## **DECLARATION**

I declare that this thesis is the result of my own work. It has not been submitted to any other institution or for any other qualification.

## **SUMMARY**

### **1. Literature review: Psychological factors influencing sexual adjustment in people suffering from chronic physical illness.**

A literature review on the influences upon sexual adjustment following a chronic physical illness is reviewed. Results found that a variety of psychological, physical and social factors influence sexual adjustment. Research has explored the multiple factors, for example coping strategies and emotional adjustment. It was concluded that sexual adjustment is a complex process, which must be understood within a systemic context.

### **2. Research project: Living with multiple sclerosis: Women's experiences of sexuality and intimate relationships.**

The current study examined the impact of multiple sclerosis (MS) upon women's sexuality and intimate relationships. Eleven women with MS were interviewed. Many factors affected sexuality and whether or not the women had positive intimate relationships. Among women with MS, sexual relationships needed to be understood within the wider context of their lives. Positive relationships with significant other people, such as their partners and wider society, were important to their sense of sexuality.

### **3. Critical Appraisal**

Personal review and reflection of the research process.

## ACKNOWLEDGEMENTS

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I would like to thank Diane Watts, the multiple sclerosis team and all the women who participated in the research for all their hard work, and without whom it would not have been possible.

Finally, I would like to thank my husband Jamie for enduring, supporting, loving, thinking, feeling and being.

## WORD COUNT

### **Literature review**

<i>Main text:</i>	6,870
<i>References:</i>	1,096
<i>Total:</i>	7,966

### **Research Report**

<i>Main text:</i>	12,204
<i>References:</i>	1,266
<i>Total:</i>	13,470

### **Critical Appraisal**

<i>Main text:</i>	2,782
<i>References:</i>	0
<i>Total</i>	2,782

### **Total**

<i>Main text:</i>	21,856
<i>Including references and appendices:</i>	26,568

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**Psychological factors influencing  
sexual adjustment in people suffering  
from chronic physical illness.**

**A review of the literature<sup>1</sup>**

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<sup>1</sup> This review has been prepared for submission to the British Journal of Health Psychology.  
Notes for contributors are included in appendix a.

## **ABSTRACT**

**Objective:** Literature on the influences upon sexual adjustment following a chronic physical illness is reviewed within a biopsychosocial framework.

**Method:** Relevant databases were searched for articles with variations of the following keywords: sexual adjustment and chronic physical illness.

**Results:** A variety of psychological, physical and social factors influence sexual adjustment. The direct and indirect impact of chronic physical illness upon physiological sexual functioning has been summarised. Quantitative and qualitative research has explored the impact coping strategies, body image, self-esteem, emotional adjustment, patient and health care interactions, and cultural factors are discussed.

**Discussion:** Chronic illness can impact upon sexual health in many ways. Sexual adjustment is a complex process, which must be understood with a systemic context. Adjustment is a fundamentally emotional process, which often occurs in the context of an intimate relationship. Supportive partnerships, in which a couple communicate effectively with one another, facilitate adjustment. Negative societal attitudes towards disability may hinder the process. For many women, adjustment involves a re-evaluation of their sexuality, and an exploration of new possibilities.

## **INTRODUCTION**

Over the past decade, there has been a growing interest in the impact of chronic illness upon sexual health, and recent research has explored physical, psychological, social and cultural facets of sexuality. This research has frequently highlighted that sexual health has important consequences for quality of life.

This literature review will examine how chronic illness can affect people's sexual lives. It will review the current research on sexual adjustment following the diagnosis of a chronic physical illness, and will consider factors that influence sexual satisfaction.

### **Literature search strategy**

The following search terms were used in Medline, Web of Science and PsychINFO: *sexuality, sexual dysfunction, sexual adjustment, chronic illness, chronic health, physical illness, and physical disability* to identify journal articles published within the period of 1995-2005. Two hundred and seventeen articles were initially identified from these searches. Only 14 were appropriate for the literature review due to irrelevancy of topic, article duplication, article being unpublished or not written in English (see appendix a for further details). Book chapters and cited references were used to locate other relevant papers. Both qualitative and quantitative research papers were reviewed.

### **The importance of uniting sexuality and chronic illness**

Chronic illness has been defined as "all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave

residual disability, are caused by non-reversible pathological alterations, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation or care" (p9, Mayo,1956).

Over twenty-five years ago Zilbergeld (1979) wrote about the lack of discussion concerning the importance of sexual expression for chronically physically ill people "...sex is a way for people to remain close to their partners and feel comforted at a time when much in their lives are bleak and painful. Having sex can be a temporary escape from the harsh realities of a difficult situation" (p239, Zilbergeld, 1979).

Anderson and Wolf (1986) wrote a progressive and frank article highlighting the importance of considering sexuality within the context of chronic illness. They claimed that sexuality is often overlooked in health care because sex is viewed as irrelevant to the recovery and management of good health. However, the significance of partner relationships at all stages of illness and recovery was reported by Dehaan and Wallander (1988) and more recently by Juraskova et al (2003). Because psychological factors are sometimes neglected in medical settings, patients' emotional reactions are too rarely considered in the context of their sexual difficulties (Anderson and Wolf, 1986). Furthermore, discussion around sexuality is frequently omitted because many health care staff are not comfortable or competent in dealing with sexual issues, and clinicians often assume that the causes of sexual dysfunction are purely disease based (Anderson and Wolf, 1986). There has been progression since the articles by Zilbergeld (1979) and Anderson and Wolf (1986). Sexuality is increasingly discussed in rehabilitative medicine; there are specific publications on sexual

health in rehabilitation and staff training. Despite this, Dunn (1997) claims that sexual health issues continue to be evaded by services.

Ducharme et al (1993) defined sexuality as “the integration of physical, emotional, intellectual, and social aspects of an individual’s personality that expresses maleness or femaleness” (p763). According to this broad definition, sexuality plays an important role in many aspects of our lives, such as companionship, intimacy and love, and can shape aspects of our personality (Rotberg, 1987). Sexuality is deeply personal and is expressed and experienced through the full scope of the senses. The whole body is involved in the complex interplay of physical and psychological processes of sexuality, and satisfactory sexual experiences depend upon the successful interaction of these elements. It is important to understand that these processes are embedded within environmental and social contexts, and might be influenced by a myriad of factors. Difficulties in any part of this wider system might lead to sexual difficulties.

### **SEXUAL ADJUSTMENT IN CHRONIC PHYSICAL ILLNESS**

Formal definitions of sexual adjustment are rare within the literature. Researchers have generally used pragmatic definitions of sexual *satisfaction*, in the context of sexual dysfunction. Bancroft et al, (2003) argues that the term “sexual dysfunction” suggests that sexual difficulties are a direct result of some “malfunction”. The term ‘sexual dysfunction’ in the current paper will be used when defined as such by authors.

Mona, et al (2000) define sexual adjustment as “self-reported thoughts and/or feelings of well-being in terms of the ways in which individuals view themselves as sexual human beings” (p123). However, this definition does not seem to reflect the process of dealing with *changes* that might occur as a result of a physical illness, and finding ways to achieve post-illness sexual harmony. In her extensive work on adapting to chronic illness, Charmaz (1995) defines adapting to impairment as “altering life and self to accommodate to physical losses and to reunify self and body accordingly” (p657). Perhaps a sufficient definition of sexual adjustment could unify both definitions: “altering the ways in which individuals view themselves as sexual beings to accommodate physical losses and to reunify self, sexual self and body accordingly”. This definition does not assume that an individual will return to pre-illness levels of sexual functioning, rather, adjustment is conceived as achieving harmony with their new situation.

## **PHYSICAL FACTORS**

Sipski and Alexander (1997) argue that when examining the impact of chronic illness upon a person’s sexual life, the following physical and psychological factors need to be examined: direct impact on genital sensation and function, (i.e. impotence in men and vaginal dryness in women), secondary complications that may prevent sexual activity occurring (i.e. incontinence, pressure sores, spasticity and fatigue) and medication side effects and additional health problems.

Many chronic physical illnesses can affect sexual functioning, such as cancer, diabetes, multiple sclerosis (MS), spinal cord injury (SCI) and traumatic brain injury (TBI) to name only a few (for further information see D’Ardenne, 2004;

Mona and Gardos, 2000). The following section summarises various ways that chronic physical illness impacts on sexual functioning and sexual relationships.

### **Direct impact on genital sensation and function**

Some chronic physical illnesses can directly impact upon the genital organs by disturbing the blood flow or the neurological information that they receive. For example, cancer can affect various sexual organs such as the testicles, penis or prostate, the cervix, breast, vagina or vulva. This may result in sexual dysfunction in any or all of the main stages of the sexual response cycle: arousal, excitation and orgasm (Masters and Johnson, 1966).

Multiple Sclerosis causes neuronal degeneration through demyelination, which can cause motor and sensory problems. This neurological damage can cause loss of desire, decreased libido, decreased intensity or frequency of orgasm and women may experience decreased vaginal lubrication (Burgess, 2002). Men may experience ejaculatory problems and difficulties in achieving and maintaining an erection (Smeltzer and Kelly, 1997). McCabe (2002) investigated relationship functioning and sexuality among 381 people with MS and compared this with 291 participants from the general population without MS. People with MS had higher levels of sexual dysfunction and indicated lower levels of sexual activity

There has been considerable research into the impact of SCIs on sexuality. Kreuter, Sullivan, and Siösteen (1996) explored the determinants of sexual adjustment by comparing the sexual experiences of 64 men and 11 women with a SCI with a control group (comprising 119 men and 36 women). They found

that those with a SCI scored significantly lower on the sexual activity and satisfaction scales. 'Many' participants with SCIs reported 'loss of mobility and sensation' and 'insufficient ability to achieve and maintain an erection' as factors that impeded their sex lives<sup>2</sup>. Unfortunately, the authors did not enumerate this finding more precisely. A weakness of this study was that differences between the data from male and female participants were not analysed. A further limitation was that a wide-ranging age group was used (19-76 years), but the pattern of ages was not described. Age can be influential in sexual health for men and women (Sipski and Alexander, 1997), yet, no analysis was conducted as to the impact of age on any of the variables. However, a strength of this study was the use of a randomly chosen, age- and sex- matched control group, which is unusual for studies in this area of research. The inclusion of a control group is particularly important in sexuality, because of the variance in sexual health across the "normal" population. In this study, predictors of higher levels of sexual adjustment were different in the MS and control groups. Much more emphasis was placed upon perceived partner satisfaction (the higher the better) and having a wider repertoire of sexual behaviours in the MS group than in the control group.

### **Secondary difficulties**

"Secondary difficulties" refer to disease related difficulties that indirectly affect that sexual response (Foley and Sanders, 1997). For example, MS can lead to a range of problems that can make it more difficult to have sex, such as spasticity, incontinence, extreme fatigue and cognitive problems. Dupont (1996) assessed sexual functioning in 116 men and women with MS and their partners.

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<sup>2</sup> The questionnaire asked some open ended questions



Dupont concluded that both men and women with MS were similarly affected by tiredness, spasms, and numbness.

### **Medication side effects and additional health problems.**

The medication and treatment regimes for chronic physical illness can impact upon sexual functioning. For example, hormonal treatment for breast cancer can result in vaginal dryness, and cancer surgery can result in vaginal shrinkage caused by formation of scar tissue, resulting in painful penetration. Prostate cancer is the most common form of cancer, and treatment can result in impotence, retrograde ejaculation and incontinence (Waldman and Eliasof, 1997). Furthermore, surgery to remove malignant tumours can result in disfigurement that affects body image and emotional health (Monga, 2002).

Ganz, Desmond, Belin, Meyerowitz and Rowland (1999) examined predictors of sexual health in female survivors of breast cancer. Vaginal dryness was a significant predictor of lower sexual interest and higher levels of sexual dysfunction. Chemotherapy treatment for cancer can also trigger the menopause, disturbing sexual functioning due to reduced oestrogen. Similarly, routine treatments of MS symptoms include medications that have side effects associated with sexual dysfunction (Foley and Sanders, 1997).

Research has demonstrated that sexual satisfaction is not *dependent* on the quality of sexual functioning. Phelps, Albo, Dunn and Joseph (2001) investigated the predictive capacity of sexual desire, erectile function, orgasmic capacity, relationship satisfaction, sexual repertoire and perceived partner sexual satisfaction on sexual adjustment in 50 men with a SCI. Their results

indicated that erectile functioning, orgasmic capacity and genital sensation were *not* related to sexual behaviour, enjoyment or satisfaction. However, this is a relatively small sample based on male military veterans (aged 20-83), which compromises the generalisability of the findings.

The research strongly suggests that physical functioning can affect sexual adjustment. However, it also suggests that sexual functioning does not exclusively account for post-injury sexual adjustment and other psychosocial factors need to be considered. This research also demonstrates the importance of health care professionals discussing sexuality in the context of physical changes *and* medication.

## **COPING STRATEGIES**

Coping strategies have been widely researched in health psychology, and coping style is related to psychological adjustment among people with chronic physical illness . For example, McCabe (2002) tested whether coping strategies are predictive of sexual satisfaction, relationship satisfaction and sexual dysfunction in people with MS. Three-hundred and eight-one people, including men and women with and without MS, completed the Ways of Coping questionnaire as part of a wider battery of measures. For men, the strategy of "focusing on the positive" predicted higher levels of sexual functioning. For women, a "detached" coping strategy predicted poorer sexual satisfaction. For men and women without MS, different coping strategies were predictors of sexual satisfaction, such as "seeking social support". However, a methodological weakness of this study was that those without MS were not asked what their actual coping strategies were, but were asked how they would

envison coping with a chronic illness. This raises doubts about the reliability and validity of this finding. Despite this, a strength of this study was its large, randomly selected sample and control group.

Coping strategies have also been explored in qualitative research. Juraskova et al (2003) interviewed 20 women who had been treated for cervical and endometrial cancer, focusing on their experiences of post-treatment sexual adjustment. They concluded that if health professionals informed patients about all the potential side effects and complications of treatment, patients were empowered to cope more effectively. Furthermore, patients who had a 'determined and realistic attitude' and participated more actively in their treatment were less distressed by the process. This was an excellent example of qualitative research using Grounded Theory, in which a coherent audit trail was presented, and an inclusive model of sexual adjustment was developed.

## **BODY IMAGE**

Body image has been defined as one's attitude toward and perception of one's body (Slade, 1994). Body image plays an important role in chronic physical illness. Mackelphrang (1993) observed that atrophied limbs, spasticity, urine bags and the need for physical assistance could all contribute to low sexual self-image. This seems likely given that body image also has strong links with depression, anxiety, and low self-esteem (e.g. Kostanski and Gullone, 1998). Societal attitudes to disability can be very damaging and "for some, disability is seen as the anti-thesis of attraction" (p976, Taleporos and McCabe, 2002a). Taleporos and McCabe (2002a) explored how seven people with physical disabilities experienced social attitudes towards physical difference, and how

this affected their body image. They concluded that all the participants had internalised negative social attitudes towards disability, but that some had come to accept their bodies. In these interviews, some participants were able to separate *looking sexy*, based on society's ideals of beauty, with *feeling sexy*. This seemed to facilitate a distinction between body image and sexuality, which enabled the women to have some control over feeling sexy. For both men and women, focussing on the more positive aspects of their bodies and having a positive self-identity contributed to positive adjustment to physical disability. A weakness of this research was that the participants were a small sample of disability activists who might not be representative of the wider population. However, their accounts of their experiences were extremely articulate and enlightening, and the use of purposive sampling strategies that aim to generate 'information rich', rather than representative findings has been advocated in a review of qualitative methodologies (Patten, 1990).

Ganz et al (1999) undertook two large quantitative studies on female survivors of breast cancer. They found that poorer body image was a significant predictor of reduced sexual interest in both groups (n = 472; n = 662) and predicted lower sexual satisfaction in the first (n=472). Although they did not discuss this finding, it may relate to the disfigurement resulting from surgery (Monga, 2002). This research has many strengths, for example, the large sample size, the large battery of measures and the use of a second study to validate the findings from the first. Furthermore, participants were recruited from a wide range of medical units in two large US cities, and include a relatively large sample of women from different ethnicities. However, not all the participants were randomly selected. One weakness of the study design was

that by making the *a priori* distinction between dependent and independent variables, the analysis was blind to the possibility of interactions *between* the dependent variables, and of the impact of the dependent variables upon the independent variables.

Juraskova et al (2003) interviewed women and found that following a hysterectomy, a women's body image was closely linked with her perceptions of femininity. Women who linked femininity with their ability to bear children experienced a more acute sense of loss with the removal of their uterus, and reported a poorer body image and lower self-esteem. These findings were more evident in younger (pre-menopausal) women who had not fully established their families.

## **SELF-ESTEEM**

Self-esteem reflects a baseline of worth, value, liking and acceptance of self that one carries at all times regardless of objective reality (Rodgers, 1951). Rodgers (1951) referred to self-esteem as the extent to which a person likes, values, and accepts him- or herself. Ones' self-esteem is influenced by unconditional positive regard from significant others. Sexual self-esteem<sup>3</sup> appears to be closely linked with sexual adjustment. Mona et al (2000) explored the applicability of Cognitive Adaptation Theory in sexual adjustment in 195 people with SCI, as measured by the Sexual Self-esteem subscale of the Sexuality Scale. An example of a question from this subscale was "I am a good sexual partner". They concluded that high levels of sexual self-esteem correlated very strongly with higher levels of sexual adjustment.

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<sup>3</sup> Defined in this study as a positive regard for and confidence in the capacity to experience one's sexuality in a satisfying and enjoyable way, (p122, Mona et al, 2000)

Taleporos and McCabe (2002b) looked at the predictive power of sexual esteem, body-esteem and sexual satisfaction on depression and self-esteem in people with disability. They argued "if people with disabilities were sexually satisfied and felt good about their sexuality and their body, they were more likely to have high levels of self-esteem" (p178). The researchers obtained questionnaire data online from 1,196 men and women with and without a disability. They found that body esteem was more closely associated with self-esteem in disabled women, while sexual esteem was more closely linked with self-esteem in disabled men. They hypothesized that this difference was related to societal pressures placed upon women to be beautiful and upon men to be able to perform sexually. This finding concurs with Helminiak (1989), who suggests that sexual self-acceptance is critical for the development of positive self-esteem. However, there were some problems with Taleporos and McCabe's (2002b) study. Although they used a large sample of people, with a wide range of disabilities, ages, sexual orientations and educational levels, it was a convenience sample and the disability and non-disability groups were not matched. Unfortunately, there were some important differences in the demographics of the two groups. For example, the people with disabilities were mostly American whereas the group without disabilities had a larger proportion of Australians. Thus, the conclusion that differences between the groups that were attributed to the presence or absence of disabilities might be confounded by cultural and ethnic factors.

Koch et al (2002) investigated the "constructions of sexuality" in twelve women living with MS. Analysis was based on participatory groups and individual interviews. In this study, appearance and personal acknowledgment emerged

as important themes. For these women, looking good and taking time and energy over their appearance contributed to feeling sexy. It was also important for them to feel acknowledged and validated by others in their lives. Feeling affirmed by people who were important to them positively influenced their self-identity. Kralik and Koch (2003) also concluded that positive reactions from a sexual partner engendered personal and sexual validation.

## **EMOTION AND SEXUAL ADJUSTMENT**

The role of mood in sexual adjustment has been examined in a number of quantitative studies. Kreuter et al (1998) found that in people with brain injuries, low mood was significantly correlated with low sexual interest and sexual satisfaction. This concurs with previous findings that depressive symptoms were negatively correlated with sexual adjustment for people with SCIs and for the control group (Kreuter et al, 1996). Similarly, Ganz et al (1999) found that higher levels of depression and anxiety predicted lower levels of sexual interest and sexual satisfaction, and higher levels of sexual dysfunction. These findings seem commonsensical, considering that loss of libido is a key symptom of depression, and a side effect of some anti-depressant medications (Weiner and Rosen, 1997).

Manstead (2005) recently argued that emotion and social relationships are intimately intertwined, but that "until relatively recently [emotion] had not been a focus for psychological theory and research" (p484). Indeed, the understanding of emotionality in sexual adjustment is neglected in the quantitative research. However, most qualitative studies in this area consider emotional issues in relation to sexual adjustment.

One study that particularly emphasises the importance of emotional issues is Ekland and Lawrie (2004), in which ten women were interviewed about sexual adjustment post-SCI. The participants reported that after experiencing a SCI sex became less of a priority for them, and they avoided thinking about it. As time went on, the women became increasingly anxious about their ability to perform sexually, and were fearful of being rejected by their partners. However, as they started to feel more comfortable with their bodies, they felt more confident and attractive, and experienced a growing awareness of their sexual selves. The authors discuss how this emotional journey to adjustment could be facilitated by good quality communication with partners. A strength of this study was that a clear audit trail was presented, in line with published standards for qualitative research (Elliot, 1999). For example, the authors reported the interview questions, socio-demographic characteristics of participants and personal characteristics of researchers. Also, they fed-back their themes to participants and amended the results accordingly. However, the themes that emerged from the research appear to be derived directly from the questions that were asked. This might suggest that they reflect the researchers' pre-conceived ideas, rather than the participants' reported experience. However, confidence in these findings might be increased by the fact that another similar study by Richards et al (1997) reported similar results.

Richards et al (1997) conducted a qualitative exploration of the experiences of 15 women with SCIs, and also concluded that the women initially "closed down" their sexual selves. This process seemed to involve a separation between the women's physical and emotional selves, and was sometimes accompanied by



depression, reduced body image and fears of partner rejection or abandonment. This appeared to be a well-conducted study, which presented a comprehensive audit trail.

In summary, both qualitative and quantitative studies indicate the importance of emotional issues for sexual adjustment. The qualitative studies discussed suggest that the wider context of partner relationships is critical to understanding these emotional issues.

## **RELATIONSHIPS**

Partner relationships have consistently been found to be central to sexual adjustment. Both qualitative and quantitative studies on chronic illness and sexuality have found the quality of participants' sexual relationships to be closely related to their overall satisfaction with the non-sexual aspects of their relationships (e.g. Ekland and Lawrie, 2004; Ganz et al, 1999; Kreuter et al, 1996 Phelps et al, 2001, Taleporos and McCabe, 2002a, Westgren et al 1999). This is also the case for people without disabilities (Kreuter et al, 1996, McCabe, 2000). Sexual intimacy is an important vehicle of contact and expression; "no act can be quite so intimate as the sexual embrace...and...satisfying love relationships are essential for [people's] personal happiness" (p232 Regan, 2000).

It is challenging to enumerate the factors that might contribute to feeling satisfied in relationships. Nevertheless, some researchers have been ambitious enough to attempt to define and measure these factors. Kreuter et al (1996) and Ganz et al (1999) both found that personal sexual satisfaction can be

dependent on perceived partner enjoyment and satisfaction with the sexual relationship. Lower sexual satisfaction was associated with a participant's partner experiencing sexual difficulties (Ganz et al, 1999). In Kreuter et al's study, they concluded that participants reporting a wide-ranging repertoire of sexual behaviours (i.e. involving sexual fantasy and experimentation), were more sexually satisfied than those with a limited repertoire (1996). Similarly, both Ekland and Lawrie (2004) and Richards et al (1997) concluded that sexual exploration played an important part in the re-evaluation of sexuality that accompanied sexual adjustment. Furthermore, both studies emphasised the importance of partner communication to facilitate this process. Richards et al (1997) concluded that the participants' sexual self-esteem was related to their perception of being desired, and that this was highly sensitive to their partner's capacity to confront sexual issues.

Effective and honest communication within a relationship was important in maintaining a positive and satisfying sexual relationship (Kreuter et al, 1996). In Koch et al's (2002) study all the participants who were in relationships (9/12) said that communicating with their partners helped them to cope with MS. Furthermore, communication was reported to be an ingredient of good sex, both before and after the onset of MS. This concurred with other qualitative studies. Richards et al (1997) and Ekland and Lawrie (2004) concluded that the ability to communicate with a partner and to be open about one's sexual health needs promoted post-injury sexual and non-sexual adjustment.

Purnine and Carey (1997) investigated the importance of interpersonal communication in facilitating sexual adjustment in heterosexual couples. They

found that agreement between partners' sexual preferences was significantly related to sexual adjustment. More specifically, a man's understanding of his partner's preferences was linked to the sexual adjustment of both partners; however, a woman's understanding of her partner's sexual preference was significantly related to her, but not his satisfaction. Clearly, partners must communicate effectively to achieve an understanding of each other's sexual preferences.

Agreement and understanding within people's sexual lives may facilitate 'relationship cohesion' (Buss, 1988). In Kreuter's (1998) study of people with traumatic brain injuries, participants who were sexually dissatisfied with their relationship commonly reported that their partners were unwilling to communicate with them about sex.

A number of qualitative studies suggest that a key role of sexual relationships for women suffering chronic illness is to deepen and strengthen their partner relationships. Thus, the emotional intimacy from a sexual relationship is reported as more important than the act of sexual intercourse. For example, Juraskova et al (2003) found that for women who were adjusting to cancer treatment, sexual satisfaction was more closely related to factors around sensuality, disclosure and reassurance than to sexual intercourse.

Westgren and Levi (1999), in a qualitative analysis of eight women's experiences of sexuality after suffering a SCI, emphasised the importance of understanding the meaning of sex for the participants. They argued that importance of the women's sexual relationships was woven together with the

wider importance of their relationships with their partners. Most of the women agreed that physical closeness and intimate touch was very important, regardless of whether they enjoyed sexual intercourse. Unfortunately, this paper has considerable limitations. Westgren and Levi (1999) claimed to have used Grounded Theory to analyse the transcripts, but there was little evidence supporting this. The results were not presented thematically, but were arranged according to the questions asked in the interviews. The quotes were disordered, and it was unclear what questions were being colloquially posed by the researchers and what were the direct quotes from the participants. Thus, these results need to be interpreted with some caution.

In research conducted by Taleporos and McCabe (2002a) regarding body image and physical disability, intimate partners' reactions to participants' bodies critically influenced the interviewees' feelings of bodily rejection and acceptance, as described in the following interview quote: "*There are times when I think, I'm too fat, I need to lose some weight, but then I think: 'Who cares? There's someone who loves me just the way I am'*" (Phoebe, p977, Taleporos and McCabe, 2002a). Thus, it seems that strong evidence from both qualitative and quantitative methodologies indicate that the quality of partner relationships is important to sexual adjustment to chronic illness. Thus, the impact of chronic illness on partner relationships is an important area of consideration. In a quantitative study on the impact of MS on spouse relationships, Dupont (1996) concluded that MS significantly impacted upon the sexual lives of those diagnosed with MS *and* their partners, whom generally reported high levels of sexual dissatisfaction. The change and loss associated with chronic illness and disability seems to demand major adjustment from

people's partners and families. Perhaps unexpectedly, some of these changes may be positive. Karlen (2002) criticised contemporary research as too focused on dysfunction and not on positive functioning, and therefore, not fully reflecting people's experiences. Karlen's (2002) qualitative study of women with Lupus reported that for some women, in spite of physical and emotional difficulties, coping with Lupus *enhanced* sexual function and relationships.

In summary, supportive relationships are crucial to sexual readjustment for women with a chronic illness. Good communication within partner relationships may facilitate a re-evaluation of sexuality, which is helpful to adjustment. Furthermore, being positively acknowledged by others may assist in the reconstruction of self-identity. However, chronic illness also impacts upon partner relationships. Understanding the way that partners meet this challenge together might be an important area for future research.

## **PATIENT AND HEALTH CARE STAFF INTERACTIONS**

Nearly twenty years ago Anderson and Wolf (1986) wrote about the importance of clinical staff in facilitating the process of sexual adjustment. Recently, this has been supported by research by Juraskova et al (2003), which examined the role of patient-doctor interactions in predicting sexual adjustment in female survivors of cancer. The participants were less distressed by the side effects that had been explained to them than by unforeseen side effects. Juraskova et al (2003) recommended that patients should be informed of the implications of cancer treatment on sexual functioning prior to treatment.

In their interviews with ten women with SCI, Elkand and Lawrie (2004) found that sexual health clinicians had been a common source of information for the women. However, the information was only helpful when it came at the right time, and many women reported that they were not ready to hear about sexuality when it was brought up. This fits with the stages of adjustment proposed by Juraskova et al (2003) and Richards et al (1997), which propose that post-injury, most women cut off, avoid or emotionally detach themselves from their bodies. In Elkand and Lawrie's study, women suggested that they would have felt less overwhelmed if they had first been given brief basic information. In the study by Richards et al (1997) participants reported a general ignorance on the part of health professionals regarding sexual education and relationships.

These studies have important implications for health care professionals. It seems that information about sexual functioning must be made available to people, but delivered with great sensitivity to a person's stage of sexual adjustment. It seems important to provide brief, basic information in the first instance. However, it is also important to discuss in advance the possible implications of procedures and medications for sexuality.

## **DISCUSSION**

In summary, there are relatively few papers specifically addressing sexual adjustment to chronic physical illness. A serious limitation in the literature is that sexual adjustment is rarely defined conceptually. Instead, sexual adjustment is defined pragmatically in terms of changes in sexual satisfaction scores before

and after illness onset. However, this is a fairly crude measurement, which does not take into account changes in meaning and emotional responses.

The physiological effects of chronic physical illness can impact directly or indirectly upon individuals' sexual health. Genital functioning may be directly affected, and secondary physical difficulties such as fatigue or pain can also hinder sexual activity (Dupont, 1996). Kreuter et al (1996) found significantly reduced levels of sexual activity and sexual satisfaction in people with a SCI compared with a control group. Procedures and medications can also impact upon sexual health. This is something that health care professionals need to be aware of, particularly in light of research linking sexuality and quality of life (Anderson and Wolf, 1986). However, in a study by Kreuter (1998) none of the 92 participants with TBI received any sexual information after their injury. Sexuality should be routinely considered as part of holistic assessments across health care settings.

Studies examining coping strategies suggest that having realistic, involved and determined coping strategies can facilitate higher levels of sexual satisfaction and good sexual adjustment to having a chronic illness. This was found in both qualitative research (McCabe, 2002) and quantitative research (Juraskova et al, 2003). Interestingly, in the latter study, those participants who felt prepared and informed about the side-effects of cancer treatment experienced less post-treatment distress. Again, this emphasises the importance of health care staff informing patients, and empowering them to be actively involved in their treatment.

Both qualitative and quantitative studies have concluded that chronic illness can have a significant detrimental affect on body image, and that this impacts on sexuality (Taleporos and McCabe, 2002; Ganz et al, 1999). Taleporos and McCabe (2002) emphasise the powerful influence that Western ideals of beauty can have upon the way people view themselves. Findings from Ganz et al (1999) suggest that people of different ethnicities had different patterns of sexual adjustment. However, the mechanisms by which culture and ethnicity affect sexuality are poorly understood, and require further research.

Sexual self-esteem has been defined as confidence in the capacity to experience one's sexuality in a satisfying and enjoyable way (Mona et al, 2000). Only two studies have directly measured self-esteem with regard to sexual adjustment. Mona et al (2000) found that self-esteem was very closely correlated with sexual self-esteem and Taleporos and McCabe (2002b) concluded that body esteem was closely associated with self-esteem in women and sexual self-esteem closely associated with self-esteem in men. Koch et al (2002) concluded that the relationship between body image and self-esteem is best understood in the context of personal relationships. It was important for the women in their study to look good, and to be acknowledged as a sexual woman.

Partner relationships emerged as a central theme in sexual adjustment. Both qualitative and quantitative studies have found a close relationship between participants' satisfaction in their sexual relationship and their satisfaction with the non-sexual aspect of the relationship (e.g. Ekland and Lawrie, 2004; Ganz et al, 1999). These findings suggest that sex is enmeshed with broader, emotional aspects of the relationship. This notion concords with the findings of a



number of qualitative studies, which suggest that a key role of sexual relationships for women is to deepen and strengthen their intimate relationship. For example, Juraskova et al, (2003) concluded that for women adjusting to cancer treatment, sexual satisfaction was more related to engaging in intimate emotional activity, rather than to sexual intercourse.

Effective communication within relationships has emerged as important to both sexual satisfaction and sexual adjustment in a number of studies (e.g. Purnine and Carey, 1997). Richards et al (1997) suggest that effective communication allows a couple to explore new sexual possibilities, which facilitates adjustment. However, the onset of a chronic illness places substantial pressures on people's relationships (Dupont, 1996), and there is a dearth of research on the factors that make relationships resilient to these pressures. In particular, there has been very little research with couples or the partners of people with chronic illness. This is unfortunate, given the obvious importance of the relationship for sexual adjustment.

A number of qualitative studies have emphasised the importance of emotion in sexual adjustment to a chronic illness. For example, Ekland and Lawrie (2004) describe adjustment as an emotional journey from a cut-off state of avoidance, through anxieties and fears to a burgeoning confidence and an awakened sexuality. This study has some important clinical implications for health care professionals. The women in the study reported feeling overwhelmed by the information they were given when they first received their diagnoses, and would have preferred more basic information. It is important to remember that the

emotional and cognitive processes are linked, and to be sensitive to a person's emotional state when delivering information.

In conclusion, chronic illness can impact upon sexual health in many ways. It is clear from the literature that sexual adjustment to a chronic illness is a complex process, which must be understood with a systemic context. Adjustment is a fundamentally emotional process, which often occurs in the context of an intimate relationship. Strong, supportive partnerships, in which a couple communicate effectively with one another, facilitate adjustment. Negative societal attitudes towards disability may hinder the process. For many women, adjustment involves a re-evaluation of their sexuality, and an exploration of new possibilities.

## **METHODOLOGICAL LIMITATIONS**

### **Relationship direction**

Much of the research on 'predictors' of sexual adjustment fails to acknowledge the feedback between and within variables. For example, some articles describe results as causal rather than correlation (Taleporos and McCabe, 2002b). This can cause difficulties when interpreting statistical data in which reciprocity exists between multiple factors (Stiles et al, 1998). Qualitative methodologies can help one to make sense of these dynamic processes by exploring and understanding these reciprocal systems. Researchers can veer away from specific and pre-determined questionnaires to facilitate a deeper understanding of any issues not previously considered or reflected in quantitative research (Karlen, 2002). Qualitative and quantitative methodologies

have different strengths and weakness, and have the potential to complement each other very well.

### **Gender issues**

There is a striking gender bias in research in this area. The majority of quantitative research studies focus on men, while the qualitative research almost exclusively focuses upon women. It would seem that there is a need for researchers to address the current imbalance in the literature.

### **Range of measures**

Almost all the studies described used different measures to examine sexuality, relationships and the other factors that were examined. Sandel (1997) made the same criticism in her literature review of sexuality after a traumatic brain injury. This makes it very difficult to reliably compare the studies, and can potentially cause lack of cohesion in the literature base (Sandel, 1997).

### **Cultural factors**

Relatively few studies have focused upon on the impact of ethnicity and the prevalent cultural context on sexual adjustment. The majority of the research on sexual adjustment was conducted in Sweden, Australia, UK and USA, mainly with Caucasian participants. A notable exception is the study by Ganz et al (1999), which had a large sample that included people of various ethnicities. Unfortunately, they compacted categories into white, African-American and non-white other, rather than reporting the specific ethnicities of all the participants. However, they found significant differences between women's sexual satisfaction based on ethnicity. Although the reasons for these differences are

not clear, it is clear that ethnicity does have an impact upon sexual dysfunction. Further research is needed to explore the mechanisms by which ethnicity impacts on sexuality.

### **Sexual orientation**

The majority of research in this area has been conducted on heterosexual couples. Furthermore, two studies specifically excluded homosexual individuals (Purnine and Carey, 1997; Westgren and Levi, 1999). In a time where being a lesbian *and* disabled is doubly oppressive (Gillespie-Sells, Hill and Robins, 1998), it seems that literature should hear and support the voices of all those who may be affected by chronic illness. The experiences of the women researched by Gillespie-Sells, Hill and Robins (1998) suggest that others' attitudes and behaviours lead some people with chronic illness and disabilities to feel as if their relationships are inferior, and that they should be asexual. Thus, it seems likely that those whose bodies are devalued by society may devalue themselves, and that this may impact negatively on their sexual self-esteem. Given these findings, it is surprising that sexuality and relationships has had a low profile in the UK disability movement (Shakespeare, 2000).

### **Drop out rates**

When describing procedures, a number of studies report high levels of people declining to participate (e.g. 24% agreed to partake in Phelps et al's study, 2001). However, only Kreuter et al (1998) discussed the impact of volunteer bias. It may be that participants who agree to take part in the research on sexual health are a distinct sub-set of the "normal" population.

## **CONSIDERATIONS FOR FUTURE RESEARCH**

### **Life stage**

Juraskova et al (2003) found that the impact of cervical and endometrial cancer treatment upon sexual adjustment was influenced by the women's age and whether or not they had children. To date, no research has examined the experiences of younger women with chronic illness in relation to sexuality. Most studies in this area have included participants from a wide range of ages: from teenagers to octogenarians. Sipski and Alexander (1997) assert that the impact of a chronic physical illness will depend on when in life it occurs. Similar to the findings of Juraskova et al (2003), Zivadinoz et al (1999) reported that current age, in addition to age of onset of MS, affects sexuality in people with MS. It would be interesting to explore whether younger women share the same experiences regarding sexuality as those in the other studies.

### **Combined approaches**

There exists a clear gender bias within the literature between qualitative and quantitative approaches with women generally being neglected in quantitative research and men in qualitative research. To redress this imbalance, women should have a greater presence in quantitative research and the experiences of men should be explored within qualitative approaches. Furthermore, researchers need to consider combining approaches.

### **Range of chronic physical illness**

Sipski and Alexander (1997) argue that whether a disease is static or progressive can impact upon the sufferer. They state that uncertainty, the need

for constant adaptation and declining physical and psychological health can harm sexual lives. A large number of studies here examined the impact of SCIs upon sexual adjustment. In these instances the injury is predominantly stable and sexual adjustment may be very different in people living with progressive or unstable illnesses such as MS or Lupus (SLE).

### **Partner relationships**

The current review demonstrates the importance of relationships in post-chronic illness sexual adjustment. However, the views of partners are relatively unheard. Dupont (1996) examined the sexual lives of partners and found that MS impacted upon the sex lives of spouses. Juraskova et al (2003) attempted to interview partners in their study but only two volunteered. The importance of partners' views and systemic influences need to be considered in future research, especially as satisfactory sexual relationships and satisfactory relationships in general are instrumental in the rehabilitation process and post-illness health.

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## **Appendix a**

### **Literature review search strategy**

<b>Search term combinations</b>	<b>Search engines</b>	<b>No. of articles generated</b>	<b>No. of articles used</b>
Sexual dysfunction and physical illness	PSYCHinfo	3	0
Sexual dysfunction and physical disability	"	3	0
Sexual dysfunction and chronic illness	"	10	0
Sexual dysfunction and chronic health	"	0	0
Sexual adjustment	"	61	7
Sexual adjustment and physical illness	"	0	0
Sexual adjustment and physical disability	"	2	0
Sexual adjustment and chronic illness	"	5	0
Sexual adjustment and chronic health	"	0	0
Sexuality and physical illness	"	15	1
Sexuality and physical disability	"	23	1
Sexuality and chronic illness	"	37	3
Sexuality and chronic health	"	1	0
Sexual dysfunction and physical illness	Web of Science	2	0
Sexual dysfunction and physical disability	"	2	0
Sexual dysfunction and chronic illness	"	7	0
Sexual dysfunction and chronic health	"	0	0
Sexual adjustment	"	10	0
Sexual adjustment and physical illness	"	0	0
Sexual adjustment and physical disability	"	1	1
Sexual adjustment and chronic illness	"	1	0
Sexual adjustment and chronic health	"	0	0
Sexuality and physical illness	"	0	0
Sexuality and physical disability	"	0	0
Sexuality and chronic illness	"	0	0
Sexuality and chronic health	"	0	0
Sexual dysfunction and physical illness	Medline	2	0
Sexual dysfunction and physical disability	"	2	0
Sexual dysfunction and chronic illness	"	6	0
Sexual dysfunction and chronic health	"	0	0
Sexual adjustment	"	14	0
Sexual adjustment and physical illness	"	0	0
Sexual adjustment and physical disability	"	0	0
Sexual adjustment and chronic illness	"	0	0
Sexual adjustment and chronic health	"	0	0
Sexuality and physical illness	"	1	0
Sexuality and physical disability	"	4	0
Sexuality and chronic illness	"	5	1
Sexuality and chronic health	"	0	0
		217	14

**Women living with Multiple Sclerosis:  
Women's experiences of sexuality and  
intimate relationships.**

## **ABSTRACT**

**Objective:** To examine the impact of multiple sclerosis (MS) upon women's sexuality and intimate relationships.

**Method:** Eleven women with MS were interviewed about their experiences of their sexual lives and intimate relationships. Interviews explored the diagnosis of MS, current or previous partner-relationships, how the women viewed themselves sexually and their relationship with their body. Interpretative Phenomenological Analysis identified common themes in the participants' accounts.

**Results:** Many factors affected sexuality and whether or not the women had positive intimate relationships. Four super-ordinate themes emerged: managing adversity, feeling different, acceptance and the meaning of sex. These four super-ordinate themes contained 10 sub-ordinate themes. Each theme is illustrated with verbatim extracts from the women's interviews.

**Conclusions:** This study demonstrated that among women with MS, there was a need to understand sexual relationships within the wider context of their lives. Positive relationships with significant other people were important to their sense of sexuality. The sexual difficulties they experienced were influenced by these significant relationships, and whether they adopted positive coping strategies.

## **1. INTRODUCTION**

Chronic physical illness has been defined as “all impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alterations, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation or care” (p9, Mayo, 1956). Chronic illness can impact upon many areas of an individual’s life including sexuality, defined as “the integration of physical, emotional, intellectual, and social aspects of an individual’s personality that expresses maleness or femaleness” (p763, Ducharme et al, 1993). Sexuality has a significant role in central areas of our lives, such as affection, companionship, intimacy and love, and it can shape aspects of our personality (Rotberg, 1987). Dehaan and Wallander (1988) and Jurascova et al (2003) have highlighted the significance of partner relationships and sexual satisfaction upon illness recovery.

Many factors can affect the impact of chronic illness on a person’s sexuality, including their individual characteristics, the specific illness, whether they have physiological effects on genital function, secondary difficulties (e.g. fatigue), whether the disorder is static or progressive, side-effects from medication and additional medical problems (Sipski and Alexander, 1997). In addition, many other psychological and cultural issues can impact upon the relationship between chronic physical illness and sexuality.

Multiple Sclerosis (MS) is a degenerative auto-immune condition of the central nervous system, and is caused when one’s immune system attacks the myelin sheath that covers neurons. This may affect motor, sensory, visual, coordination,



bladder, bowel, sexual and cognitive functions, and may thereby significantly affect sexual functioning in many ways.

The sexual difficulties that have been identified with MS have been categorized into primary, secondary and tertiary causes (Foley and Sanders, 1997). *Primary difficulties* are a direct result of the neurological impairment, such as decreases in desire, libido, intensity or frequency of orgasm, vaginal lubrication in women, or impotence in men. *Secondary* difficulties result from other interfering physical changes, such as fatigue, muscle spasm, incontinence or pain. Some MS medications can also affect sexual arousal (Smeltzer and Kelly, 1997). *Tertiary difficulties* refer to the psychological, social and cultural issues that can interfere with sexual functioning such as depression and body image.

Sexual difficulties are significantly more prevalent in people with MS than in the general population (McCabe, 2002). Precise figures are uncertain because of methodological disparities, but Dupont's literature review (1995) suggested it might affect between 50-90%, with men apparently affected more. However, men are more assertive in accessing professional help for sexual problems than women, who appear relatively more reluctant, possibly leading to significant under-reporting (Dupont, 1996; Osborn et al, 1988). Another gender difference in coping with the impact on sexual relationships is that women appear to place greater emphasis on discovering emotional coping techniques, while men are more concerned with finding ways to achieve sexual satisfaction (White et al, 1993).

## 1.2 Chronic Illness, Women and Sexuality

Hwang asserts "a disability impacts not just on the physical aspects of sexuality, but also the emotional, psychological and social elements of a woman's self-image as a sexual being" (p128, 1997). The person with a chronic illness has to adapt to a new body-image, defined by Charmaz (1995) as "altering life and self to accommodate physical losses and to reunify self and body accordingly" (p657). According to Tepper (1997), men learn from an early age that their manhood is tied to their penis whereas women learn that society still judges a woman's attractiveness and desirability largely on standards of physical perfection (Whipple and McGreer, 1997). The expectations of how 'real' women look and behave have a huge impact on the sexual identity of a disabled female (Hwang, 1997). For women, pregnancy and motherhood may constitute a vital part of sexual identity (Hwang, 1997). Juraskova, et al (2003) found that following a hysterectomy, a women's body image was closely linked with her perceptions of femininity. Women who linked femininity with their ability to bear children reported a poorer body image and lower self-esteem. These findings were more evident in younger (pre-menopausal) women who had not fully established their families. MS often occurs during young adulthood (Burgess, 2002) and many women fear an exacerbation of symptoms during pregnancy and are worried they will not be able to adequately care for themselves or their families (Smeltzer and Kelley, 1997). Information about pregnancy and MS is contradictory (Smeltzer, 1994), however, it is advised that women seek help and support post-partum to enable women to have adequate sleep (Smeltzer and Kelley, 1997).

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### **1.3 Previous Research**

There is little research on the lived experiences of women with MS in relation to their sexuality. Koch et al (2002) examined the experiences of 12 women aged 30-60 with MS. They used five focus groups, and subsequent individual interviews to explore how the women "constructed their sexuality". The women regarded sex as an important part of life, and sexuality had multiple meanings shaped by life experiences. What was important was looking good and feeling attractive to others, feeling positively valued by others, and having good communication with partners. The emergent themes relating to personal experiences may have been contaminated by the use of focus groups. In addition, the research group was from a cohort of 30-60 women (age range unspecified) and to date, there has been no research looking at experiences of younger women with MS in relation to sexuality. Indeed, the majority of research on sexual adjustment following a chronic physical illness involves a wide spread of ages, from teenagers to octogenarians. The impact of a chronic physical illness will depend on when in life it occurs (Sipski and Alexander, 1997). Zivadinoz et al (1999) reported that current age, in addition to age of onset of MS, affects sexuality in people with MS. It is possible that younger women may not share the same experiences, or hold the same constructions regarding sexuality as those in the study by Koch et al (2002).

The current study proposes to increase our understanding of sexuality and intimate relationships in young women with MS through an in-depth exploration of young women's personal experiences, previously neglected within the research literature. In contrast to Koch et al (2002), a phenomenological framework will be used to ensure a focus on young women's personal experiences.

## **1.4 Aim**

- To explore how young women with Multiple Sclerosis perceive issues around their sexuality and intimate relationships.

## **2. METHODOLOGY**

### **2.1 Researcher values and interests**

Henwood and Pigeon (1992) and Elliot et al (1999) both maintain that as idiosyncratic approaches and creativity are important in qualitative research, it is important to that the researcher discloses personal values. This enables readers to critically evaluate the impact of these values on interpretation, and to consider alternative positions.

The researcher is a 29-year-old white British female from the South of England with long-standing interests in women's issues, sexual health and disability, but has no personal experience of having a chronic health condition. The researcher is currently completing training in clinical psychology.

### **2.2 Qualitative Methodology**

Radley (1999) asserts that *illness needs to be studied qualitatively because there are multiple ways in which a person is affected by, and responds to illness. It is the experience to the sufferer that mediates the relationship between the chronic illness and their bodies (Smith et al, 1999). Indeed, this experience also mediates how people think about their sexuality and intimate relationships.*

Qualitative research has been chosen for the current study for a number of reasons. Previous research has been predominantly quantitative, providing valuable statistical evidence on the frequency, severity and physiology of the problems, and thereby raising awareness of the issues (see Dupont, 1995). It is now appropriate to try to establish a holistic understanding of these findings; to focus on the 'insider's perspective' of what sexuality and intimate relationships mean to the women, rather than focusing on the disease process. This approach avoids researchers being restricted by specific and pre-determined questions, and may allow them to facilitate a deeper understanding of issues not previously considered in qualitative research (Karlen, 2002) or which are too complex to investigate quantitatively (Burman, 1997). Semi-structured interviews particularly enable researchers to gain a "detailed picture of respondent's beliefs about, or perceptions or account of a particular topic' (p9, Smith, 1995).

Interpretative Phenomenological Analysis (IPA) is chosen as it allows analysis of experiences of individuals' personal worlds (Smith et al 1999). IPA understands language as a way of expressing these experiences to other people. What participants say has some significance and 'reality' for them, which is part of an on-going self-story representing a manifestation of their psychological world. IPA's non-judgemental approach uses reflection and encouragement to elicit participant's stories, and understand their personal meanings.

Often, the way that people derive meaning from their lived experiences is not immediately obvious. The researcher must engage in an interpretative relationship with the transcript data to elicit themes (Smith, 1995), and then identify for thematic commonalities amongst interviewees' stories to facilitate a

deeper understanding of those experiences. IPA is more appropriate for this study than Discourse Analysis, which assumes that language does not *reflect* psychological and social reality but *constructs* it. Similarly, Grounded Theory is not appropriate, as it is concerned with deriving new theory from the data, where the aim of the study is to explore meanings of sexuality and intimate relationships, rather than offering an explanatory account of them.

### **2.3 Validity**

There are many approaches aiming to improve quality and “ensuring rigour while acknowledging idiosyncratic creativity in the research process” (p98, Henwood and Pigeon, 1992) and ensure that resultant themes closely reflect participants' experiences. Elliott et al (1999), proposed various criteria to evaluate quality in qualitative research. To enable readers to critically evaluate the researcher's position, the researcher's values and interests are presented. Participants' demographic characteristics are also presented. This information ensures that the reader can assess the applicability of the findings. Each theme should be clearly grounded within the text and relevant quotes presented where appropriate. Furthermore the researcher provides a clear trail of the analytic process, which is detailed with supporting documentation (for further information about the analytic process please see data analysis section). A research diary was kept to aid reflexivity within this process. Elliot (1999) and Pope, Ziebland and Mays (2000) also propose the benefits of involving others in the analytical process to minimise the potential of researcher bias. In the current research, clinical and academic supervisors with significant experience in qualitative research were closely involved in the research process at all stages. To ascertain whether researcher interpretations could be substantiated, supervisors

and fellow IPA researchers assisted at different stages of analysis; initially identifying important meanings as they arise in the text, selecting quotes and creating themes, creating super-ordinate themes for individual participants and identifying super-ordinate themes for all women. Part of this process is to ensure that nuances in the data are accounted for and integrated in with analysis (please see appendix 12 for a detailed account of the analysis).

## **2.4 Participants**

Women were recruited from the Multiple Sclerosis team in the Neurosciences Department situated in a city hospital in the North Trent region of England, where the specialist nurse was the main collaborator. Thirty patients were invited to participate who fulfilled the following criteria:

- Diagnosed as having MS by a consultant neurologist at least two-years previously.
- Aged 20 – 35 years
- Have sufficient English language skills to complete the interview.

For the current study, no restrictions were made based upon severity of illness, relationship status, sexual orientation or sexual life. The inclusion criteria did not prejudice against mental health issues as it was deemed important to include people who were experiencing psychological difficulties. Depression can be a symptom of MS (Foley and Sanders, 1997) and is a common experience of people coming to terms with a diagnosis of chronic illness (Katon and Sullivan, 1990).

## **2.5 Procedure**

The initial contact letter was sent by the MS nurse on the researcher's behalf (appendix 4), inviting participants to learn more about the research by completing a consent-to-be-contacted sheet (appendix 6). Any positive response was followed up by the researcher who discussed the purpose and details of the interview. Participants were then asked to complete a form consenting to the interview and for this to be tape-recorded (appendix 7). Participants were asked to complete a health questionnaire, socio-demographic questions and then a semi-structured interview. All participants were interviewed in their own homes.

## **2.6 Ethical approval**

The South Sheffield Ethics Committee approved the study (appendix 2) and the Sheffield Teaching Hospital Foundation NHS Trust gave Clinical Governance approval (appendix 2).

## **2.7 Method of data collection**

### ***2.7.1 Health questionnaire***

In order to enable the reader to critically evaluate the research, Elliott et al (1999) proposed that the participants' demographic characteristics are presented. In order to offer the reader more descriptive data regarding the participant's physical and mental health, participants were asked to complete the SF-36v2 (standard version, appendix 8). This is a current health status questionnaire containing 11 items assessing physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional lives and mental health. The questionnaire offers two final summary scores; physical functioning and mental



health. This has been used in various health care settings with good internal consistency ( $\alpha=.75 - .85$ ) and reliability (.60 -.89) (Roberts et al, 1997).

### **2.7.2 Semi-structured interview**

The interview schedule is a tool devised prior to the interview allowing the researcher to consider what they might want the interview to contain. This schedule directs and guides conversation into the researcher's realm of enquiry, but the flexibility afforded by the semi-structured techniques ensures the interview is not dictated by the schedule. Smith (1995) argues that this facilitates rapport with the participant and the researcher is free to pose further questions and follow the participants' particular perspectives.

The interview schedule was constructed according to Smith's (1995) comprehensive article on semi-structured interviewing, in partnership with the project supervisors, and the MS nurse specialist (appendix 9). It covered the following areas:

- The experiences of MS diagnosis
- The experiences of any partner relationships since diagnosis
- The experiences of intimate and sexual relationships before and after diagnosis
- The experiences of their sexual selves before and after diagnosis
- Their relationships with their bodies before and after diagnosis
- The experience of the interview

An introductory question pertaining to the participant's diagnosis of MS was felt appropriate to starting a dialogue on women's personal stories, and allow an

easy move into the realms of any partner relationship, and to act as a springboard to other questions. Questions on sexuality and intimacy would come later when the interviewer had time to build a relationship with the participant.

Interviews explored personal understandings and meanings of these themes, and all these experiences were deemed to be important to the women's experiences. In order to capture the richness of the themes emerging from the women's talk, the researcher followed up avenues of importance to the participant to enable the participant to give a more detailed picture.

The interviews were scheduled to last between 50 and 75 minutes. They were audio-taped, and subsequently transcribed verbatim, using a specific format for analysis (appendix 11), and finally checked for accuracy by the researcher whilst listening to the tapes.

## **2.8 Data analysis**

The analysis was conducted in the following stages, according to Smith et al (2003). After careful error checking, each transcript was re-read by the researcher to identify any prominent statements that described experiences, feelings and meanings. They were then re-read to highlight any emerging themes, whilst attempting to remain as close as possible to the meanings that these hold for the individual women.

Throughout, thematic clusters and connections within the transcript are sought, and gradually super-ordinate themes that could embrace and subsume other smaller themes were identified. During this process, the researcher returns to

individual women's transcripts to ensure that emerging sub-ordinate and super-ordinate themes are closely tied to the interview. Once all the interviews were analysed, a master table of themes was produced, with quotes to evidence the process.

### **3. RESULTS**

Fifteen women responded to the research invitation. One participant (who was above the age criterion) agreed to be a pilot interviewee to assess the quality of the interview schedule. This pilot transcript was not analysed. A further twelve women were interviewed. The transcript from one woman was excluded from analysis as she had a diagnosis of bi-polar depression resulting in sexual difficulties with separate issues from her MS.

The final group of eleven interviewees were aged between 25-34 years and to preserve anonymity socio-demographic characteristics are given in summary. Ten were in long-term heterosexual relationships and six were married. Seven women were in the same relationship they were in when diagnosed. Two women have since started new relationships to the ones they were in when diagnosed, one woman was single when diagnosed and one woman has divorced the partner she was with when diagnosed and remains single. The women had been diagnosed with MS for between 2-13 years and six had a formal diagnosis of relapsing-remitting multiple sclerosis. All the women described their ethnicity as white British. Five of the women had children.

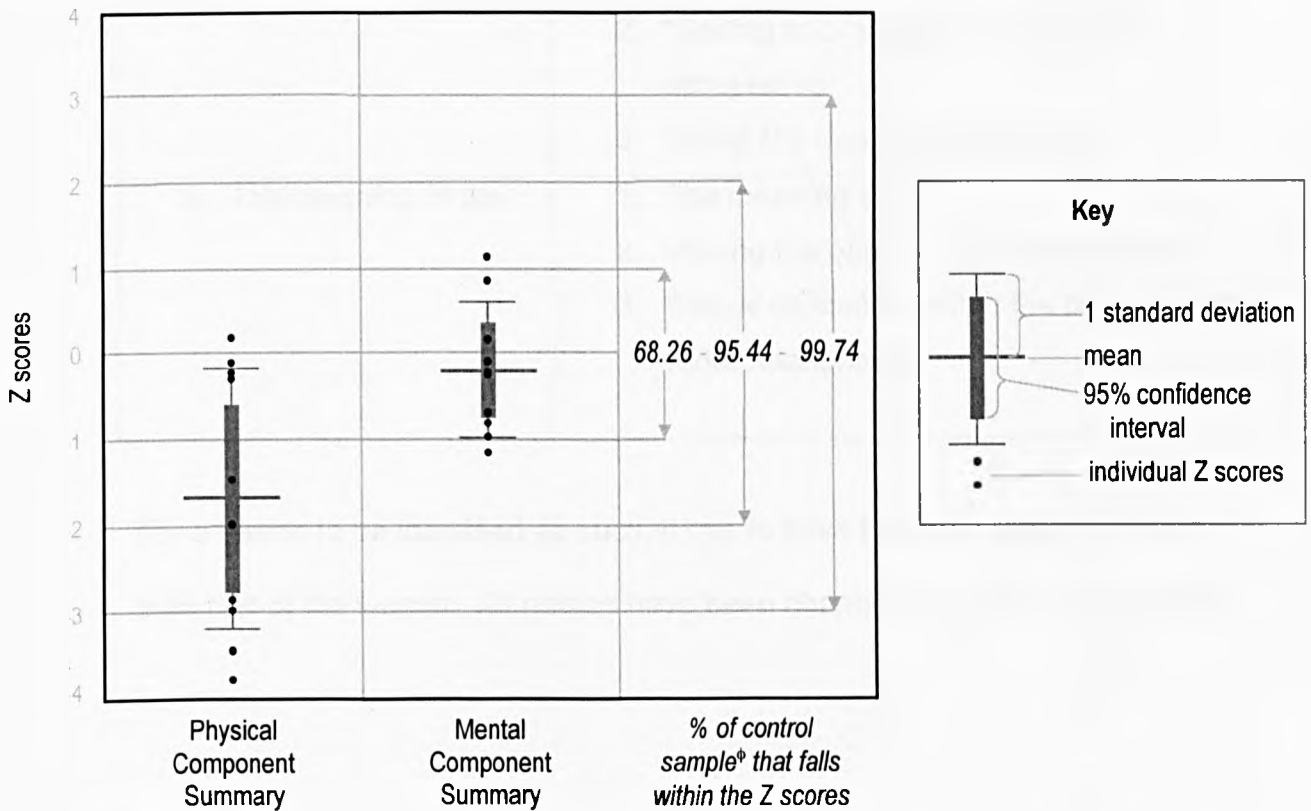
#### **3.1 SF-36 Questionnaire**

Ten of the eleven participants self-completed the SF-36. One participant did not because of an administrative error. The control data was from 275 US women aged 25-34 (Ware et al, 1994). These data were used to calculate the Z score.

The mean Physical Functioning Component summary score was substantially below the norm, which was statistically significant ( $Z=-1.69$ ;  $t$ -test  $P=0.007$ ; CI

95% = -2.79 – -0.60), whereas the mean Mental Health Component score was not significantly different from the norm ( $Z = -0.18$ ;  $t$ -test  $P = 0.47$ ;  $CI\ 95\% = -0.72 – 0.36$ ). The participants' scores on the two scales were not correlated (Pearson's  $r = 0.26$ ,  $P = 0.47$ ).

**Figure 1. Graph showing spread of Physical and Mental Component Summary scores in relation to a control sample<sup>φ</sup>.**



<sup>φ</sup> Control sample characteristics: 275 US women, aged 25-34.

### **3. 2 Semi-structured interviews**

Despite the research being about intimacy and sexual relationships, the participants discussed many issues that created a context within which to understand the complex relationships that subsume sexuality. The table of themes (figure 2) reveals the complexity of sexuality.

Figure 2. Table of themes

<b>SUPER-ORDINATE THEMES</b>	<b>SUB-ORDINATE THEMES</b>
a) Managing adversity	<ol style="list-style-type: none"> <li>1. Living with "definite" uncertainty</li> <li>2. Reframing adversity</li> </ol>
b) Feeling different	<ol style="list-style-type: none"> <li>1. I just want to be treated normal":</li> <li>2. Comparison with others</li> </ol>
c) Acceptance	<ol style="list-style-type: none"> <li>1. Acceptance by others</li> <li>2. "Getting in or staying out": Partner acceptance</li> <li>3. Fitting MS into the relationship</li> </ol>
d) The meaning of sex	<ol style="list-style-type: none"> <li>1. The meaning of sex</li> <li>2. Making the effort for sex and sexiness</li> <li>3. Sexual difficulties within the context of the wider relationship</li> </ol>

For a theme to be identified as such, it has to have been discussed by more than half of the women. All names have been changed to preserve anonymity.

### **3.3 (A 1) LIVING WITH DEFINITE UNCERTAINTY**

*"like we all live with uncertainty but when it's like definitely uncertain, definitely if you, you know what I mean, most people don't sort of think about the uncertainty".*

The above quote by Lucy plainly highlights the uncertainty that the majority of the women in the study struggle with. Their uncertainty concerned future symptoms and their future ability or disability. For some women such as Kate, uncertainty meant that seeing into the future was impossible:

*"I don't think too much of the past nor do I think about too much in the future, it's just...going on a day-to-day basis",*

In the quote below, Linda talks about the emotional impact of the unpredictability:

*"with MS it's so unpredictable one minute...like I said one minute you feel great and you can fight Mike Tyson and at other times you just think you know that's it but that's all part and parcel of multiple sclerosis you've got it, you know it's not going to go away and bog off "*

For Kim, the uncertainty of future symptoms causes concerns for pregnancy and knowing that it may cause a significant deterioration in her abilities:

*"it's like, obviously pregnant women get tired, erm, easily, erm, and it would be just like, well, I'd be like, well, I'm tired already, hold on and I've*

*got that tiredness on top of it, it would be like, I'd be asleep all day, you know what I mean? It's like scary what, what would, what would happen and how it would happen, and if it would stay like that or would I get better again?"*

The women's uncertainty about their future extended to concerns about their relationships, and the implications of MS on their partner. Because of the unpredictability of MS, many women offered their partner an exit from the relationship (discussed later). In the following quote, Izzy talks about how she perceived the impact on her partner:

*"it's a lot to take on, you know, you know you've got this girlfriend whose having your child but he had no life ahead of him, you know to be stuck with, with the unknown"*

This certainty of an uncertain future caused the women to feel powerlessness in relation to their bodies and their lives. Ruth articulately described the feeling of powerlessness in her deconstruction of the word 'attack' which is commonly used to represent a multiple sclerosis relapse:

*"attack because that... the word attack is all to do with either military or, erm, somebody jumping out and, erm, beating you up or something on the street or something, it's a very messy picture of something really external...and very unpredictable"*



### **3.4 (A 2) REFRAMING ADVERSITY**

Whilst the women were discussing issues involved with living with MS, many seemed to reframe some of the difficulties that they were experiencing with a more positive spin. For some, it was about re-affirming their new outlook, re-prioritising what they wanted from life or changing how they interpreted their situation. In the following quote, Claire re-affirms her decision to change her lifestyle to one very different from her peers, and promotes her new life style change as one that everyone should consider:

*"they're quite ambitious and they want quite a lot of money and they want you know the sort of person who want a lot of money and a really nice house and all the nice things and the nice holidays, and I'm not saying that I don't want any of that but to me now, being, for anybody not just me but I think being healthy is more important than most things"*

Kate also reframed the impact of MS to involve explicit positive statements:

*"so although it's taken stuff away, we always feel grateful because it's given us, do you know it's like, given us a lot in return as well, it's taught us a lot of things"*

Linda reframed MS as something she would not allow to have control over her:

*"I've been given this disease so I've got to accept it and, and half the time I forget and I do forget because I will not let it, let it win me"*

For many of the women, coming to terms with *disability* per se is a difficult journey. However, Sammy and Heather took great pride in their strong sense of independence and had to positively reframe the utility of a wheelchair in order for it to become more acceptable. Heather:

*"there's things out there to help me and make my life more bearable and easier, I either take them or I be stubborn and I don't go out, I become a recluse or, do you know what I mean"*

### **3.5 (B 1) "I JUST WANT TO BE TREATED NORMAL"**

The women talked about feeling normal and abnormal, and being treated differently by others in relation to how they view themselves. Being treated differently caused considerable fear in some women. Often women recounted stories of being treated with disdain by others, especially whilst in a wheelchair. Here, Claire is discussing her relationship with the world when poorly:

*"you don't feel a part of ...the world anymore you just feel like a bit on the periphery and everyone else is busy doing what they normally do"*

Many women also talked about their reluctance to tell others for fear of differential treatment. Lucy:

*"...If I ever did, you know, end up in a wheelchair or something, people like that would be very sort of, they think they're being caring but they're actually being very patronising...just because you can't walk doesn't*

*mean that you're not, you know, still there mentally at the moment...I would hate that to happen"*

However, the women did not want to be treated differently, as highlight by Jane:

*"...It makes me feel like...I don't know, I'm expected to be a special, I don't know, expected to be treated differently to everybody else because I've got this wrong with me and that wrong with me, you know, and I just want to be treated normal"*

Whereas, the majority of women felt different from wider society, Kim in fact saw herself as different to those with MS and the same as those without MS:

*"Yeah, it was as if, as I'd gone and helped...you know, a helper that had gone to, erm, sit with them and show them where things are or whatever. It was, you know what I mean, it was, you feel like one of them people that, yeah, I didn't feel like I was one of them"*

In many interviews, there were particular references to assumptions that wheelchair users have cognitive impairments, and various words and euphemisms were used to describe a fear of being in a wheelchair, such as "cripple", "cabbage", "vegetable" and "mentally retarded". Indeed, this is how some people felt treated by other as Jane describes in the following excerpt<sup>1</sup>:

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<sup>1</sup> Please note R denotes researcher and P denotes participant

*R: Okay. And you were saying about the wheelchair is that you don't like using it, or you don't use it if you don't have to.*

*P: If I don't have to use it then I won't.*

*R: What is it about using the wheelchair that you don't like?*

*P: Because in some places, if I want information about something they'll sort of answer me mum if she's pushing me or my dad, you know, and I feel like saying, excuse me, it was me that asked the question, and I have done that once or twice, I don't like doing it but I don't like being talked over.*

Gemma felt that she was not like everybody else because of her MS:

*R: You feel like you're not a normal woman. What, what do you mean by that? I was wondering if you could tell me a bit more about that?*

*P: Well, having, oh, I don't know...I can't describe it in words. I think it's just not being like everybody else.*

*R: And how is everybody else?*

*P: They have a perfect life.*

### **3.6 (B 2) COMPARISON OF SELF WITH OTHERS**

When the women were talking about their difficulties they often used other people, with or without chronic illness as anchor points to compare themselves with. For some women, it seems that the purpose of this comparison was to highlight issues that made their position more favourable compared to others. Furthermore, this was also about 'reframing adversity', because it gave the women a sense of personal validation: For example, Heather whose physical

disability was quite severe, compared herself to a friend in a similar position who was less independent. This enabled Heather to retain a sense of her own valued independence:

*“it could be a lot worse, you know, my friend’s profoundly deaf with MS, erm you know, she hasn’t, she’s widowed at a young age, what a life, she hasn’t really got a great quality of life, you know whereas I’m quite independent, I still have my independence”*

Claire compared her new lifestyle and priorities to people without MS. This comparison served to reinforce her decision:

*“even people without MS are completely stressed out like are flaked out at the weekends and things and we look at them and think well I think I’ve definitely made the right decisions so I’m quite happy with that sort of life I’ve chosen”*

In the following quote, Lucy discusses her hospital visit to discuss receiving Beta-interferon therapy. Specific comparisons with other people with different health conditions, and comparison within a wider global context, offers her a sense of perspective. Lucy saw herself as “down to earth” and seemed to use these comparisons to ground herself:

*“afterwards we just sort of, both went to the pub and we were talking about it, and it was very sort of, you know thinking well, do I really want to inject myself once a week for the next ten years or the rest of my life*

*but then it was also like well think of diabetics they have to do it every day and sort of taking their, looking at the wider picture again where there's far more traumatic stressful horrible things happening in the world, this is not a big deal, so it's a bit sort of, probably has helped us get some perspective"*

However, for some women, comparison served to demonstrate a hopeless or devalued position in relation to others. Gemma felt as if her life was worse than other women's because she had MS:

*"I think everyone's [life is], I don't know...better"*

Ruth also compared her situation to others with diabetes. However, for her it served to highlight her lack of control with regard to MS and her general sense of powerlessness:

*"I resigned myself to the fact that I haven't got a method of control and I don't expect to have one, but there's loads of people who have conditions that they have no control of, I have erm my grandfather with diabetes and erm he was controlled by diet for years"*

### **3.7 (C 1) ACCEPTANCE BY OTHERS**

The role of acceptance from both others and partners seemed to be very important in these women's lives, although acceptance from partners had a more fundamental impact upon them. In the absence of acceptance from partners, the role of 'others' becomes more influential. It seems that all the interactions

between self, partner, ex-partners and others offer current different influences that can serve to aggravate difficulties or act as a buffer against them. For Jane, in the absence of a partner, the influence of friends seemed to take a greater importance. Jane appreciated their physical support and the way they normalised her use of the wheelchair:

*"I said, well, I'm not going to town because I'll have to go in the wheelchair, you know, she was saying, oh, there's loads of people that go in wheelchairs, you know, you'll be alright, and I'm like, well, no I won't, because I wouldn't do that...I mean, they're brilliant, they do help, you know, if I'm struggling to walk or go anywhere, they do hold me, you know so they are really, really good"*

Claire felt that the support offered by her friends, family and work colleagues were significant in helping reduce many potential stresses. In the following quote, Claire talks about the flexibility offered by work that protects her physically and emotionally:

*"if you have sort of buffers like that like flexi time and like people who are understanding and the thing is like that can make all the difference with thinking you're not worrying about well I don't feel very well but its only three o'clock I'll have to stay till five"*

Some women talked about when their friends withdrew their support. Kate talked about MS "*separate[ing] the wheat from the chaff*" and spoke about a

*“good friend and a person worth knowing, they stick by you whatever”* Heather had a similar position:

*“your real friends stay around, you, your friends that aren’t so real soon disappear because they don’t, they can’t handle it”*

### **3.8 (C 2) “GETTING OUT OR STAYING IN”: PARTNER ACCEPTANCE**

Sharing and acceptance appear fundamental to the security within the relationship. Sharing involved bringing MS into the relationship and both partners taking responsibility for the disease (describe in theme 4a). However, the women in the study talked about their need to feel accepted both for the MS, and despite of the MS. Many women had given their partner the option of leaving the relationship as a result of the MS. A partner's choice to remain in the relationship was seemingly demonstrative of acceptance.

Heather’s partner initially found it very difficult to accept the MS and as a result she felt she needed to know whether he was able to accept the difficulties that MS may present with:

*“if you’re going to be with me and I have got MS... you really have got to appreciate that at some time in the future you may be looking after me you know, and that’s a big burden... and it’s a big thing so...that was his time to either...get out or stay in and he chose to stay in”*



Ruth talked about support in terms of sacrifices that her partner made in moving to be nearer her family. In the following quote, Ruth talks about offering her husband the option to leave the marriage as a result of the MS diagnosis:

*"if given the nature of what they've now diagnosed, given the nature of what it's done to me, if you wanted to, to walk away then I'd understand...you might think, well, this is just so horrendous and I can't watch Ruth go through this, so you can walk away if you want"*

Furthermore, acceptance involves the partner being involved in making changes in the relationship and both partners adapting to new roles, especially that of partner-carer. In the following quote, Sammy talks about her partner's acceptance, which encompassed her use of the wheelchair, the evolution of partner-carer roles and offering her alternative perspectives to difficulties she faced. To Sammy, these factors demonstrated that he accepted her disability:

*"I still can't really believe how easily Aaron has accepted how things are going...we went shopping... there's no way I could possibly have walked round [it] then, and... I'd got the wheelchair in the back and I dared to bring up the...daren't say it to him... so I didn't get out the car and he kept saying what is wrong, why won't you come in, and I did say to him, I'm going to need my wheelchair...but I, I don't want you to push me and he, he just couldn't understand why, and I said, because you are my partner, you're not my carer, and I wanted a distinction between the two...and he said, well that's okay I'm going...to do some shopping, you can just sit in the car... or you get in your wheelchair and you let me*

*push you, I got in the wheelchair and... now it's just an automatic thing, he gets the wheelchair out the car... I'm kind of quite surprised at how he's adapted to that...because he says well... you've just got a pair of wheels making you go round rather than your legs".*

Lucy talked extensively about the ever-changing nature and evolution of her relationship and hypothesised that this is why they are still together. In the following quote, Lucy talks about the shift from "being the carer" to "being cared-for" within the relationship. Later she talks about how they are "very evenly matched...very equal" within the relationship and how these new roles are being shared equally:

*"like I probably used to be the more solid, down to earth, stable one that had, had to look after Tom sometimes but that got switched...probably when I got my diagnosis and shortly before and he had to be the rock."*

### **3.9 (C 3) FITTING MS INTO THE RELATIONSHIP**

One of the major issues for women was to share the responsibility and burden of MS with their partner, rather than taking on the burden independently. This feeling of being supported is synonymous with feeling that their partner had accepted the MS, and seemed to result in a greater sense of security in the relationships. Lucy defined the move from independent responsibility for the MS to shared responsibility as a seminal moment in her starting to "fit it in" to her life and starting to deal with what it meant for them:

*"I think last, last year was quite, erm, sort of seminal in our coming to terms with it, so I think somehow we...well, it sort of came into the relationship and we, erm, accepted it as part of our relationship as well, not just a part of me, something we'll both have to deal with"*

Izzy acknowledged that for her, a defining moment was the hospital staff treating her and her husband as a unit, enabling them to both deal with MS in a united way:

*"to me, me and my husband are a unit...we come as one, and when I'd go to visit [hospital]...lunchtime would come along with a sandwich and with the buns and, drink and things and, you know me husband would get the same...we are a unit and he's got to deal with it as much as I have, so I felt that it brought him into the situation that we had"*

However, Jane, who had a partner at the time and who was pregnant with their first baby emphasised the importance of MS as a joint experience. However, she felt that staff at the hospital did not treat them as a couple:

*"nobody said anything in front of him because he was my partner, not my husband, you know, they waited for my parents to be there or my mum to be there to tell me anything"*

For Kim, knowing her partner will share the burden of MS, at whatever cost, is very important. Here Kim is paraphrasing what her partner said to her:

*“whatever happens, we’ll just face it together then, you know, whatever, whatever other things, whatever happens in another relapse we’ll just get through it or get by it”*

### **3.10 (D 1) THE MEANING OF SEX**

The impact of both sharing MS and acceptance from partners was explored previously. Indeed, the role of partner acceptance impacts upon other areas of the partner’s shared life, such as intimacy and sexual relationships. Partner acceptance seemed to offer the women a sense of security in their relationships that directly impacted upon the meaning of sex to them.

The majority of the women described sex as a way of strengthening their relationships, and sex being a physical demonstration of their emotional world, feeling together and differentiating the partner relationship from other relationships. The following quote from Heather illustrates these features:

*“Just the...the closeness... it’s something you don’t have with anybody else, with your husband...you can sort of, tell him your inner most thoughts without feeling daft or stupid...you share your worries and things like that with them, which I do erm, because he has been there at my lowest times... you’re just sharing something that, just two of you and nobody else can get in-between that...it’s nice to feel that closeness and that sort of trust, mutual respect...makes you feel a bit more secure really.”*

Sammy and Kim also talked about some other benefits of sex, for example, feeling wanted by their partner, which then contributes to their sense of security within the relationship. The following quote is from Kim:

*"It's just being close and, and the intimacy between us. I mean, it's like, like I said, it's not, it's not half as much these days, erm, but it's just, it's just so nice that somebody wants you and, I mean, I know that he wants me anyway, not just, not just for the sex...we connect like that"*

The priorities for sex seemed to differ between the women. For Kate, Linda and Sammy sex was equally as important for both them and their partners. Kim felt that sex was more important for her than for her partner. Kate was keen to engage in sexual intimacy despite feeling unwell:

*"if I had a bad day or if I'm not feeling brilliant, you know, there's times when you, you want to have sex still, do you know what I mean, and, and I've tried to explain to him but he says but no, but it's not right because you're not well or you're feeling poorly, but if I only had sex every time I felt absolutely damn perfect, I'd be like a celibate"*

However, for other women, such as Gemma, Izzy, Ruth, Jane, Claire and Lucy sex was driven more from the male perspective. The following quote is by Ruth:

*"I really fancy, erm, that aspect of the intimate relationship and that it can be romantic and it can be fantastic and all the rest of it but it always does seem to be more driven from the male perspective"*

Jane's experience of sex with her ex-partner was that it was to meet his own sexual needs:

*"he was just bothered about getting his end away and that were it...you know, he didn't have anything, you know, he didn't sort of...I don't know, he didn't do anything to make me think, oh, right, yeah, you know"*

Gemma felt that sex was less important to her than her partner, especially when she was coping with the diagnosis of the MS that occurred shortly before her marriage. Gemma and her partner did not communicate about their sexual life until he went elsewhere for sex. For Gemma, sex was about togetherness and predominantly making her partner happy:

**R:** *...what are the good bits about being sexually intimate with Chris?*

**P:** *Ways of making him happy.*

Of the women who asserted that sexual intercourse was more of a priority for their partner, some stated that to deny them this resulted in guilty feelings:

Claire:

*"I suppose the only way and I do feel bad about it sometimes is the tiredness angle of it really in that...yeah that's just sometimes I'm that washed out and tired that all I want to do when you're in bed is just go to sleep"*

Although Ruth was not currently experiencing any sexual difficulties, she felt that the presence of sexual difficulties would be yet another sacrifice that her partner would have to make for her and as a result she would offer him the chance to leave the relationship. For Ruth, the presence of sex without difficulties represented a "normal married life" and offered her reassurance.

### **3.11 (D 2) "MAKING THE EFFORT" FOR SEX AND SEXINESS**

Within the women's sexual relationships, a central theme to emerge from the interviews was that intimacy from being together is as important for the sexual relationship as anything else. However, 'being together' takes time and effort and so making time to be together was very important not only for the sexual relationship but also for the wider relationship. "Making an effort" meant forming opportunities, being creative with time, trying different sexual positions, communicating about sex and being together on an emotional level.

Heather talks about starting to negotiate time with her partner to foster togetherness initially in a non-sexual way that represented a recent change in the relationship. Later in the interview she talked about this time as being conducive to initiating sexual intimacy:

*"I've started making the effort to actually try and stay awake, you know or I'll say to him, you know, I know it's nine o'clock and I know you don't like coming to bed early but why don't you just come upstairs now and it's not for sex, it's just laying in bed"*

Finding time and energy proved difficult for the majority of the women due to levels of fatigue, especially those with young children. Often women had to adapt by resting during the day as described in the following quote by Kate:

*"I mean it's like with fatigue...you've just got to be a little bit more creative really and, and think of ways round it, okay evenings might not, or nights might not be a good time to have, to make love so you, you think, oh I'll do it in the morning"*

Lucy was experiencing sexual difficulties prior to the diagnosis which she felt MS exacerbated through stress. She felt that "not...communicating", "not making the time" and "not working at it" were fundamental to their difficulties:

*"I mean I think, sort of, intimacy, non-sexual, we're pretty intimate and always have been, I don't think the diagnosis changed that, erm, sexually...I think it's more the, the stress of the situation...erm, did did affect it, and, and then both of us not being good at communicating about that particular subject, but I think that just made it worse because then we weren't able to tell each other what was going on in relation to sex. I just do think it's a big shame...you know...and of course it would be brilliant to have a really satisfying sex life but you need to work at it and I think at the moment we're just not...neither of us is particularly willing to put the time into it"*

Linda was not co-habiting with her partner but felt that she wanted more time for them to get to know each other and express themselves in more intimate ways:



*"like we cuddle and we never cuddled before but like now so I've explained to him I've said I don't want you grabbing hold of me hand and putting it on your [penis]"*

Making an effort was also relevant to feeling sexy and sexiness. Women talked about making an effort to get "dolled up", such as *"put your make-up on, put your nice clothes on"* (Gemma) and *"put make-up on and a skirt and, and heels possibly and I'd be dressed up"* (Ruth). Many women also talked about the need to create a context for sexiness, for Claire this was feeling rested, for others it having a meal or going somewhere different and having a personal focus on each other:

*"you're making an effort to go out, to be together and, and spend time together and inevitably that means you talk to each other and, and you're just focussed on that one other person and in that context, I tend to find it's more likely that you will start thinking about the possibility of, of going, of that ultimately leads towards to having sex"*

However, many women talked about the importance of their partners in making them feel sexy. For example, Linda said:

*"he were complimenting me all the time and made me feel sexy so I suppose compliments... it would be nice for Lee to say ah you look nice and then I feel good"*

### **3.12 (D 3) SEXUAL DIFFICULTIES WITHIN THE CONTEXT OF THE WIDER RELATIONSHIP.**

The majority of the women experienced difficulties as a consequence of MS that directly or indirectly affected their sex lives. Fatigue often presented as a barrier resulting in missed opportunities for sex, a lack of desire or women re-prioritising sex due to energies being taken by other demands. The impact of these sexual difficulties seemed to be mediated by the wider relationship. Kate experienced fatigue and sensory difficulties with resulting pain, and at times genital numbing. She still prioritised sex and became more creative with when and how they had sex. Furthermore, she talked about using alternative ways to offer her partner sexual stimulation:

*R: And is that what happens, is that sometimes what happens with your vagina? It will go numb for a little bit?*

*P: Yes, and it can be painful so I don't particularly want to, don't want sex at all.*

*R: Do you, are there other things that you do at that time?*

*P: No, because it's only, I mean I, I, well, I pleasure Simon, you tend to, with MS you tend to become an expert at oral sex (laughter) or would that be too crude?*

For Sammy, MS has resulted in reduced orgasmic sensation and increased fatigue and pain has led to a reduced sexual drive. Despite this, Sammy could still enjoy orgasmic sensation by using different sex aids, although the desire to do so had become less frequent. Sammy seemed to redefine sexual intimacy:

*"I still need, you know, to feel close to Aaron in that way because there's closeness sleeping on the settee fully clothed, watching television, having a cuddle, and there's a closeness when, when you're having a bath together, that type of a thing"*

Furthermore, Sammy felt loved and supported by her partner in many other ways. She said that feeling wanted by her partner for sexual intimacy was a powerful positive influence on how she saw herself and their relationship:

*"and that's quite nice, to know that Aaron still wants me, he still wants me all the time, no matter how bad I'm feeling about myself or how bad my MS is, he still wants me as a woman, and that makes a big difference to me"*

Izzy also experienced fatigue, pain and orgasmic difficulties. However, for her the experience was very different to that of Sammy. Izzy's general confidence was very low due to her hatred of her body and the weight she had put on and was unable to lose. Her self-esteem and sense of personal security was closely tied in with her body-image and as a result, she felt that she had nothing to offer her partner with regard to their relationship:

*"I'm thinking what's...my husband thinking, ah, she's got the shakes again and she looks this and, you know because I think, he must think, she's fat, she's not that great looking, you know she shakes all the time, she can't run anywhere, she can't do any exercise, you know what have I got going for me"*

For Izzy, sex was more of a priority for her partner than herself, but she continued to have sex despite a lack of sensation. Sexual intimacy gave Izzy a sense of security within the relationship and she was able to still offer her partner sex despite feeling that she had nothing else to offer. Izzy took solace in the closeness and intimacy it afforded her whilst prioritising her husband's sexual pleasure:

*"Erm, I don't feel anything to be fair, you know, I don't, at the time it's just, you know as long as me husbands pleased I don't really mind, but for me just having sex and, and being together and closeness and being loving together is enough sometimes, you know it's enough, it doesn't have to, but me husband feels like, you know, your turn"*

#### **4. DISCUSSION**

Current literature proposes that MS leads to levels of sexual difficulties (Dupont, 1995). These difficulties have been categorized into primary, secondary and tertiary sexual difficulties, primary being the direct physiological result of neurological impairment, secondary being physical changes which indirectly affect the sexual response, and tertiary being the psychological, social and cultural issues that can interfere (Foley and Sanders, 1997).

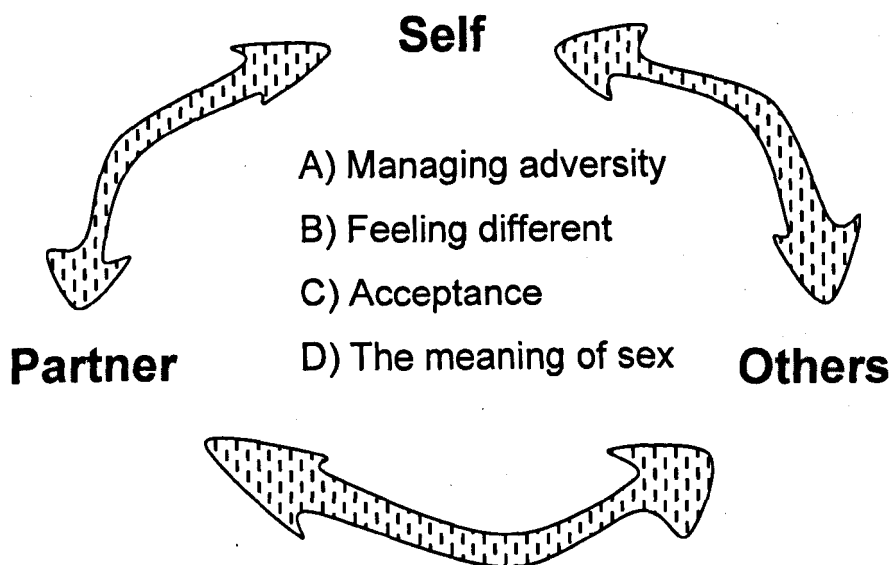
Responses on the SF-36 (v2) indicate that the women's mental health score fell within the 'normal' population compared to scores derived from a US female population, this is despite of some participants being very physically disabled as a result of the MS. The responses on the physical functioning scores indicate that the women had widely varying levels of physical disability. This may suggest that on the whole, the interviewees were well adjusted to their MS regardless of the level of disability resulting from the disease.

Four women reported symptoms of primary sexual difficulties such as vaginal numbing, decreased sensation and reduced desire. All the women in the current research experienced secondary difficulties of MS in the form of extreme fatigue, which impacted upon their sexual lives. However, the way in which fatigue impacted upon their sexual lives depended upon the context in which it occurred and the meanings that were attached to it.

It was apparent from the interviews that many factors in the women's lives affected their sexuality, whether or not they had positive sexual relationships that were still deemed as satisfying, fulfilling and enjoyable. Furthermore, it seemed

that sexual dysfunction had to be understood within the wider context of their lives. The wider context can be understood as the interaction of the three main protagonists in the women's stories; themselves, their partners and others (i.e. friends, family, colleagues and society). This global context is illustrated in the following diagram (figure 3).

Figure 3. Diagram illustrating global context



#### **4.1 (A) MANAGING ADVERSITY**

The majority of the women who were interviewed in the current study felt a great deal of uncertainty because of unpredictable changes in their symptom presentation and severity. Uncertainty about the illness progression led women to feel powerless and out of control of their bodies. They questioned the strength of their relationships, and many offered their partner the option to leave. For one woman, the unpredictability of MS made her seriously question whether or not she should consider getting pregnant. This concurs with Mullins et al (2001), who found that the heterogeneity of MS, the lack of a cure, its unpredictable course and eventual functional impairment often leaves people feeling very

uncertain about their lives, and that this uncertainty can amplify psychological distress. This uncertainty impacted directly onto the women's relationships and had profound consequences for their sexual lives.

Chronic physical illness and disability can undermine one's sense of control over one's body (Sipski and Alexander, 1997). Indeed, to a certain extent, the women's sex lives were governed by the varying MS symptoms, in being physically able to have sex, in feeling well enough to have sex or reprioritising sex (e.g. due to fatigue, energy is reprioritised for children). When faced with uncertainty, people sometimes strive to achieve control by cognitively reframing the situation (Roberts et al, 1999). The women talked about how they coped with the unwanted changes that MS imposed upon their lives by reframing adversity into something positive, manageable and even life enhancing. Moos and Schaefer (1984) used the term *cognitive redefinition* to describe the way individuals coping with physical illness accept the reality of the situation, and redefine it in a positive and acceptable way. Similarly, in Taylor's (1983) theory of cognitive adaptation, a similar concept was proposed, in which cancer patients managed to think different about the cancer, and so gained a "sense of mastery" and control. Women in the current study positively reframed adversity and thus derived a sense of mastery and control over a disease that had a constant and unpredictable presence in their lives. The theory of cognitive adaptation has been used to explore sexual adjustment in people with spinal cord injury (Mona et al, 2000). This study found that higher levels of internal personal control predicted better sexual satisfaction.

## **4.2 (B) FEELING DIFFERENT**

'Feeling different' was an important theme for many women. They talked about feeling different from others *without* MS, others *with* MS and feeling disengaged from their social world. Many women also feared being treated differently, and some had experienced being treated differently, for example, being ignored or being assumed to have an intellectual disability. The relationship between feeling different and sexuality is one that has not been examined within the quantitative literature.

Dominant societal attitudes and their portrayal in the media affect the way that able-bodied people view individuals with disabilities (Hwang, 1997). Many women were fearful of the wheelchair, an image that seemed symbolic of ultimate disability and their fears for the future. In addition, the women often equated physical disability with cognitive disability. This may be because when individuals experience late-onset chronic physical illness and disability, their attitudes and thoughts about chronic physical illness, disability and gender roles tend to be developed prior to their illness, in the context of the dominant cultural ideology (Dehaan and Wallander, 1988; Hwang, 1997). Societal pressures and attitudes can have an effect on one's sexuality. This was highlighted by Taleporos and McCabe (2002) in their research with people with physical disabilities. A significant theme to emerge from their interviews was the influence of negative social attitudes and the internalisation of these social attitudes in the interviewees. It seemed that people had to differentiate between 'looking sexy' and 'feeling sexy'. For example, women who did not live up to societal standards of female physical attractiveness by 'looking sexy' had to subjugate this concept



by an internally driven sense of 'feeling sexy'. This allowed them to still explore their sexuality and feel sexually attractive. As Hwang asserts "in a society that still often judges a woman's attractiveness and desirability largely on standards of physical perfection, women with disabilities are by definition excluded" (p119, 1997). 'Feeling different' seemed to affect how the women perceived their sexuality and whether they felt sexually attractive.

The women often made comparisons with other people (either friends or assumed others) also experiencing difficult circumstances. Some women made statements highlighting how some aspects of their life were better than other people's. Some women seemed to derive strength from comparing themselves to others in similar situations who appeared to be managing well. Similar processes of social comparison were identified in Taylor's theory of cognitive adaptation (1983). It was felt that *self-enhancement* was an effort to enhance and restore self-esteem and people either made downward comparisons (i.e. perceiving oneself as better off than someone else) or upwards comparisons (i.e. looking towards people perceived as good adjusters for inspiration).

These comparisons with other people might enhance the women's sense of personal validation and affirmation, despite all the difficulties of the MS. It seemed that still feeling able to offer something positive and desirable was very important for the woman's self-esteem, which is implicitly linked with sexuality (Helminiak, 1989; Mona et al, 2000; Sipski and Alexander, 1997; Taleporos and McCabe, 2002).

### **4.3 (C) ACCEPTANCE**

One of the most important themes to emerge from the interviews was the women's need for acceptance, from both partners and others in their life, such as friends, family, colleagues and society in general. The theme of "acceptance" reflected another's willingness to accept and tolerate the conditions of their illness, and their potential disability.

There were various aspects to acceptance. For example, it was important for the women to feel accepted with the MS and despite the MS. It was particularly important that they felt accepted sexually by their partner. Feeling supported and accepted by others acted as a buffer for various difficulties the women faced in the world, whereas the absence of acceptance exacerbated the impact of their problems. Good quality social support, generally referring to the perceived comfort, caring, esteem or help one individual received from others (Wallston et al, 1983), has been found to determine health status (Oakley, 1992). It has been hypothesised that social support reduces stress, and the absence of social support also acts as a stressor (Wallston et al, 1983). It could be suggested that the role of social support from others reduces the women's personal stress, also known to interfere with sexual functioning (Crowe and Ridley, 2000), and/or reduces the stress on the couple by sharing any burdens elsewhere (D'Ardenne, 2004).

Acceptance seemed to bridge many of the themes in the women's stories. In response to feeling different, many women discussed the importance of normalising responses from partners and others to mediate or negate their feelings of difference. For example, in situations where the use of a wheelchair

was an inevitable yet unwanted option, the women felt better if they had friends who had a relaxed and positive attitude to the wheelchair and encouraged its use. Furthermore, the women interpreted their partner staying in the relationship as a sign of acceptance. Conversely, some women found it difficult when their friends withdrew from them when told about the MS diagnosis.

For the women, feeling able to share the responsibility for the MS contributed to feeling supported and linked into feeling accepted by their partner. Sharing was represented by changes within the relationship that facilitated the evolution of new partner-carer roles. This process involved both the woman and her partner deconstructing and re-evaluating their definitions of chronic illness and disability. This process also challenged couples to re-evaluate their understanding of gender roles.

It seemed that acceptance from others fostered the women's self-acceptance and personal validation. *Social acknowledgment* was an important theme to emerge from Koch et al's study on how women with MS construe sexuality (2002). Acknowledgment was entwined with a sense of being valued by others regardless of MS. Positive interactions and feeling socially accepted and supported increased the women's self-esteem, self-confidence and perceptions of themselves as sexual beings.

#### **4.4 (D) THE MEANING OF SEX**

Many of the women discussed the need to make an effort with their sexual relationships. For example, they talked about the importance of finding time to focus on each other, engaging in different and stimulating experiences and

focusing on sexuality as an important part of their lives. Furthermore, making the effort and finding the time was also relevant to the relationship in general. Some women stressed the need for good quality non-sexual interactions to promote relationship satisfaction and therefore, sexual satisfaction. Interestingly, Kreuter et al (1996) concluded that those people with spinal cord injuries who had a wide repertoire of sexual behaviours reported higher levels of sexual satisfaction.

For the women, 'feeling sexy' was important to their sense of sexuality and was directly related to 'looking sexy'. Women talked about 'making an effort' in relation to their appearance, for example, wearing sexy clothes, attending to their hair, putting on make-up and high heels. However, knowing that their partner found them sexually attractive was as important to the women as 'looking sexy'. Similarly, Koch et al (2002), found that making an effort with one's personal appearance was highly important for women with multiple sclerosis in feeling sexy. Being accepted and acknowledged as a desirable woman is an important prerequisite to having a positive sexual encounter (Koch et al, 2002).

In the current study, although the meaning of sex involved sexual intercourse sexual pleasure was derived from more than just coitus. Intimate relationships strengthened their relationship and increased their feelings of security. It made the women feel loved and sexually wanted by their partners, thus, increasing their self-esteem and improving body image. For some women, sex represented 'normal married life'. Sexual intimacy is an important vehicle of contact and expression; "no act can be quite so intimate as the sexual

embrace...and...satisfying love relationships are essential for [people's] personal happiness" (p232, Regan, 2000).

The idea that sexual satisfaction and pleasure are derived from more than sexual intercourse is not new. Other relationship factors have also found to link with sexual satisfaction, such as the perceived sexual satisfaction of one's partner (Kreuter et al, 1996; Phelps et al, 2001), sexual agreement (Purnine and Carey, 1997) and communication (Juraskova et al, 2003). Couples reporting wide-ranging repertoires of sexual behaviours post chronic physical illness (i.e. fantasy and sexual experimentation) are more sexually satisfied than those with a limited repertoire of sexual behaviours (Kreuter et al, 1996, 1998).

The majority of the women experienced some level of sexual difficulty as a result of the MS either directly (i.e. genital numbing and/or lack of sensation), or indirectly (i.e. fatigue and/or pain). Sexual dysfunction that impacted directly on physiological functioning was experienced as a frustrating and upsetting experience. However, the women's responses and adaptations to these sexual difficulties seemed to be mediated by other influences, such as their interactions with the world, the wider context of their partner relationships, and their view of sex. The evidence suggests that sexual difficulties are exacerbated or negated by the context in which they occur.

Where the women felt accepted, sexually attractive and felt that the MS was shared in the relationship, sexual adjustment was reported. For example, some women altered thoughts, feelings and behaviours to accommodate physical losses and to reunify themselves, their sexual selves and their body. Some

women found ways to adapt to the difficulties, such as making the time and making the effort to engage in sex and feeling sexy, being creative and finding alternative ways to achieve sexual satisfaction. For some women it was about redefining sexual intimacy and having a more inclusive definition as to what sexuality meant for them.

Levels of sexual satisfaction do not always concur with levels of sexual dysfunction, and often the quality of a sexual relationship following a chronic physical illness is closely related to overall happiness in the general relationship (Ganz et al, 1999; Kreuter et al, 1996). Byers (2001) criticises existing classification schemes for women's sexual problems on a number of grounds including their failure to consider or include the relational context in which interpersonal sexual expression occurs. Byers concluded that relationship satisfaction is the most important contributor for sexual satisfaction, and improved sexual satisfaction can occur through improved non-sexual aspects of the relationship.

It has been argued the impact of a chronic physical illness can depend on the age at which the illness occurs (Sipski and Alexander, 1997; Zivadinoz et al, 1999). Qualitative research in this field has interviewed people between 19 and 64 years of age (Juraskova et al, 2003; Koch et al, 2002; Richards et al, 1997; Taleporos and McCabe, 2002; Westgren et al, 1999). The impact of an illness on young women's lives may be different to the impact of being diagnosed with an illness in later life. It was felt that any pertinent themes that directly map onto a woman's age might have been obscured in these qualitative analyses. In the current research, young women from a specific age range were interviewed (25-

34). However, it seemed evident that the issues are similar to those found in other qualitative research, regardless of age.

In the current research, many factors in the women's lives influenced their sexuality and determined whether or not they had positive and satisfying sexual relationships. Sexual dysfunction needed to be understood within the wider context of their lives and the interactions between the women, their social relationships, their partner and how they retained control over their lives.

#### **4. 5 Clinical Implications**

It is clear from this research and other qualitative research in the field (e.g. Juraskova et al, 2003; Richards et al, 1997; Westgren et al, 1999) that health care professionals place sexuality onto the rehabilitation agenda. Furthermore, health care professionals need to be aware of referral routes to other professionals who are both comfortable and experienced in sexual health issues. Any discussions regarding sexuality and sexual relationships need to be understood within the wider context of someone's life and with consideration of what it means for the person to have MS, how the person with MS views their partner and social relationships, in addition to the physical symptoms of MS.

In light of what the women discussed regarding the need for acceptance from others and good social support, services may wish to consider facilitating support groups, perhaps specifically for younger women where sexual health is openly discussed.

The issues described above not only seem relevant for women living with multiple sclerosis, but also seem to be transferable to other chronic physical illnesses and other issues that may affect body image. For example, a psychological perspective can be applied to understand people's use of mobility aids (i.e. wheelchairs) and particular treatment regimes (e.g. those resulting in weight gain).

#### **4. 6 Strengths and limitations of the research**

The current study considered the physical, social and psychological aspects of the women's lives, thus offering a more holistic understanding of sexuality and intimate relationships in women with MS than previous research. The current study uses a relatively homogeneous group of women. Qualitative research in this field has used ages ranging from 19 to 64-years-old. However, in the current study all the women had multiple sclerosis and were from a very specific age range (25-34). Using qualitative methods allowed the women to discuss issues that were important for them, and those issues that have not been examined in quantitative methods. Furthermore, the women responded with similar mental health scores in the Sf-36v2. However, this strength is also a limitation: the women were white, British, living in the North of England and all but one were in a heterosexual relationship. Thus, the findings do not account for cultural variations in ethnicity and sexual orientation. Furthermore, these women were open to discussing sexuality and their intimate relationships and may not be representative of those who chose not to participate, especially those who may be suffering psychological difficulties as a result of the MS or are at different stages of adjusting to the disease.



The findings reported the importance of systemic issues upon sexuality and intimate relationships. It could well be that the reason why more systemic information was derived was because the initial opening question asked about the women's experiences of the MS diagnosis. However, the contextual themes emerged from across the entire length of the interview and from interviewer questions and enquiries that pertained directly to sexuality.

#### **4.7 Further research**

The current research was conducted on white, British women in heterosexual relationships. It is important to understand how chronic physical illness may impact upon sexuality and intimate relationships in gay, lesbian and bisexual individuals. Gillespie-Sells et al (1998) found that lesbians have experienced considerable homophobia in the disability community groups. Further research regarding the difficulties of being doubly stigmatised within society would again offer us a more contextual understanding of sexuality and intimate relationships in minority groups. The majority of research pertaining to sexual adjustment takes place in Australia, America and Sweden with predominantly Caucasian participants. However, Ganz et al (1999) found that in a sample of 662 female survivors of breast cancer (of which 77% were white, 14% were African-American and 8% were "other non-white"), a predictor of sexual satisfaction after breast cancer was being African-American. It is preferable if research gave greater consideration to the experiences of different cultural groups.

Partners have such an influential role in rehabilitation, and chronic illness has such a significant impact onto both the lives of sufferers and their partners. However, the experiences of partners are a consistently neglected area of

research in chronic physical illness. Dupont (1995) found that MS significantly impacted upon the sexual lives of those diagnosed with MS and their partners. Spouses generally showed a high level of sexual dissatisfaction. Interviewing couples may offer a more holistic and multi-layered perspective on the meaning of sexuality and intimate relationships in people with chronic physical illness and their partners.

The combined use of qualitative and quantitative approaches is relatively rare in psychological research. However, it seems that uniting these two approaches may offer some advantages: increasing the richness of the data and potentially promoting greater validity. It would be interesting in future research to have some objective ratings of sexual difficulty and level of sexual satisfaction to run parallel with qualitative analyses.

#### **4. 8 Conclusion**

The women in the current study seemed to have good mental health, even though their level of physical functioning was lower than a 'normal' population. The sub-ordinate themes of the women's stories of managing adversity, feeling different, acceptance and the meaning of sex were best understood within a wider bio-psycho-social context. For example, the interactions between three main protagonists in the women's stories: themselves, their partners and others.

The uncertainty of the MS prognosis had a significant impact on the women's lives, and the lives of their partners. They coped with the difficulties they faced by positively reframing adversity. This process seemed to enable the women to retain a sense of control over their lives. The women often made comparisons with other people, which seemed to give them strength and a sense of personal validation. Most of the women felt different from others in some way. They feared being treated differently because of their disabling illness, and some had been treated differently.

It was important for the women that other people were accepting of them both with and without their MS. Being accepted helped women come to terms with their situation. It was important for the women to share the burden of the MS with partners or friends. For the women, 'feeling sexy' was linked to 'looking sexy' and being appreciated by their partners. Being creative within the sexual relationship was important for the women's sexual lives and intimate relationships. Sexual pleasure involved more than sexual intercourse, and sexual satisfaction was explicitly linked with the quality of the relationship in general.

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# **CRITICAL APPRAISAL**

The purpose of the critical appraisal is to reflect upon the process of undertaking this piece of research. The appraisal follows the course of the research, focusing on the various stages of the project, planning the research, interviewing and writing up. Throughout the critical appraisal, factors that served to facilitate and hinder the research will be highlighted and the issue of maintaining motivation is discussed. The section will conclude with my reflections on what I have learnt, and how this might inform my future practice.

### **ORIGINS OF THE PROJECT, WHY CHOSEN AND HOW IT CAME TO FRUITION.**

I have always had an interest in women's issues and sexuality. As part of my Masters degree I completed research on the topic of female sexual offenders. When thinking about initial research ideas, I wanted to build upon my knowledge in the area of female sexual offenders. However, I thought that it would be more interesting to build upon my repertoire of knowledge within the areas of sexuality, especially as I was planning to have a third year specialist placement at a genito-urinary department.

In order to place some limitations on the potentially overwhelming arena of psychological research I had three criteria; it had to use a qualitative approach, be related to sex, and enhance understanding of women's issues. I chose qualitative research because I had never used qualitative methods before and was incredibly interested in the process and outcome. Furthermore, I felt that if there was a time for trying out something new within the realm of academia, this was the time. I would have access to expert guidance from two supervisors who were very skilled in IPA. I knew that I would enjoy undertaking qualitative

research; it seemed to fit with my personality and my identity as a clinical psychologist. Finally, I knew that a good introduction now would leave me with the enthusiasm to complete more research upon qualification from the course and as a practising clinician.

My initial interest was in female commercial sex workers. Sheffield has very good links into this community of women with health workers meeting up with the women for sexual health advice, contraception and support. I was interested in how women constructed their sense of sexuality and defined their intimate relationships. However, for a doctoral thesis where the participants needed to be more accessible than they were, I felt this was an inappropriate and impractical research choice.

The search for a project took me to Lincoln and an impromptu chat with a rehabilitation nurse who talked about some work she was undertaking regarding sexual dysfunction with women with MS. After further conversation and literature searches, it transpired that this was an area that fulfilled all three criteria.

The next step was finding participants. Lincoln seemed to have limited numbers of people on their caseload so I initially spoke to various co-ordinators of MS groups around the North. However, according to the people I contacted, younger women tended not to frequent these groups as they were considered to be too intimidating<sup>2</sup>. I then met with the MS nurse at a hospital in the region

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<sup>2</sup> They were often attended by older people with severe MS symptoms and resulting disability.

who was very interested and enthusiastic in the area. From this point, a research proposal was devised.

### **SUMMARY OF PROGRESS AND TIME SCALE**

After finding a viable research project and making contact with an enthusiastic professional within an MS service, the next step was completing the research proposal. The MS nurse was actively involved in developing the research proposal, and a pressing issue at this point was clarifying that there was a reasonable number of participants who fulfilled the research criteria, and that we were clear how they were going to be contacted. Fortunately, the research proposal was given a favourable response by the research sub-committee and only minor changes were needed. However, making these revisions to the research proposal took longer than anticipated. Sometimes it was difficult to find convenient times when both my supervisors and myself were free. I also felt very naive in conducting qualitative research during the initial stages of the research. I was following guidance from others and did not feel confident enough to voice my opinions, which may have speeded this process up. I was granted university approval in August 2004 and received ethical approval (after some clarification and minor amendments) in November 2004.

At this time, the research project started to become more frantic, I was due to get married in the New Year and have my honeymoon at the start of January 2005. It was important that the MS nurse and myself discussed and agreed on when the information packs were to be sent out. If people were sent the participant information before Christmas, it was likely that taking part would not be a priority, and lead to reduced interest in the study. Therefore, we decided to

send them out at the start of January 2005. Participant's responses to the research were quick and more people agreed to be contacted than I had anticipated. This spurred me on and made me realise what an important subject this was. It transpired later on in the course of interviewing that the MS nurses were invaluable to the women that I spoke to, and it was the patient's respect for the MS nurses that facilitated their agreement to take part.

All my interviews were completed by April 2005 in preparation for a long study block in May 2005 to complete the analysis. However, the joy at having completed all the interviews was soon overshadowed by another academic piece of work that needed to be completed by the end of April. When I started the analysis I did not imagine that it would take as long as it did. This resulted in a much shorter time period to complete my literature review, but I remained optimistic and felt I could meet the July 2005 research deadline.

### **CRITICAL MEETINGS**

One of the most critical meetings in an early stage of the research was when my NHS supervisor and myself visited the MS nurse to discuss the possibilities of conducting research. I think having my supervisor present gave the research proposal more credence because my NHS supervisor also worked with the same NHS trust. In reality, all subsequent interactions with the MS nurse could be considered critical meetings. Throughout the time delays which resulted from writing proposals, the process of the scientific review at the University and being reviewed by the ethics committee, I had to ensure that I was in regular contact with the MS service by email, telephone or popping in to give updates. The service was facing many changes and the MS team were getting increasingly

stressed. This contact was important as it served to reassure them that it was a serious project, and worth their time and commitment.

On a personal note, a further critical meeting took place with a fellow trainee also conducting IPA. Because IPA was an idiosyncratic process, and because I had no previous experience of conducting qualitative analysis, I wanted to compare our approaches and ensure that my audit trail was appropriate. It was a relief to know that despite some differences, we both had similar approaches to the qualitative process. For example, in the way that quotes were identified and the process of identifying sub-ordinate and super-ordinate themes in the data.

## **PROCESS OF RESEARCH**

Once ethical approval was achieved, I found an appropriate pilot interviewee. This initial interview was helpful in establishing whether the range of questions in the interview schedule were clear and elicited relevant information. It enabled me to monitor my interviewing style, for example, ensuring that I was non-directive and drew out the women's experiences appropriately. I gave a copy of this transcript to both my NHS and academic supervisors who also examined my interviewing style. The feedback was constructive and helped me to think about the way I used prompts in the interviews.

Organising the interview schedule proved tricky at times. It was felt that to ask directly about the women's sexuality and intimate relationships without first forming a good rapport might affect their willingness to talk openly about their sexual experiences. It was felt that to ask women about these issues after a

period of "getting to know each other" by building a rapport and understanding their MS would elicit a larger quantity of data. The drawback with this approach was that interviews would sometimes last for as long as 2 hours. The topic of sexuality *and* their MS diagnosis was too much to ask about and I felt that at times, talk around sexuality was being slightly neglected. To account for this, I started to ensure that each question was given relatively equal weighting. Interestingly, one of the most important questions in the schedule was a finishing question; "is there anything that we haven't spoken about today that you thought we would talk about?". This elicited a wealth of further information from the women. Without the expert supervision I spoke about previously, I would never have thought to ask this important question.

Building rapport with the interviewees before starting the interview was very important to the research process. Part of building a rapport involved reiterating the purpose of the interview and gaining informed consent. However, I found very early on that it was important for the women to understand why I had chosen this topic. This seemed natural given the sensitivity of the area; I would anticipate that speaking in detail about one's sexual relationship to a complete stranger is unusual for most people. I felt that the women needed to know that I was genuine and the research reputable. I also offered information about my own background. For example, that I was training to be a clinical psychologist and this incorporated clinical work, in addition to the research. I briefly mentioned why I was interested in this area and how it linked with my work in the genito-urinary department. I also reiterated issues around confidentiality and what would happen to the tape and transcripts. This seemed to put the participants at ease. Many women had assumed that I was an undergraduate



student and were worried that other people could freely access the tapes. This process of rapport building was particularly significant for one woman who had previously had a very negative experience with a clinical psychologist.

Whilst conducting interviews I was able to utilise the clinical skills that I had learnt during my clinical training and found this exceptionally helpful. I was non-judgemental, containing and used reflective listening skills to encourage the women to expand upon what they were saying without being directive. However, drawing upon my clinical skills also caused some conflict. I had to consciously stop my analytical and clinical "hat" from interfering with my research "hat". For example, stopping myself from following up statements as I would have done in the therapy room.

The importance of self-imposed boundaries and prioritising my emotional health became apparent whilst interviewing. I did not anticipate how tiring it would be to conduct research interviews and it became apparent that I was physically unable to undertake multiple interviews in one day. Furthermore, I organised one interview on a Sunday (due the participant working during the week). However, it was clear that on a sunny Sunday afternoon, undertaking interviews was not a priority and I needed to impose firm boundaries on myself, for example only interviewing participants during the week.

When analysing the data, it was difficult to know where to start and I was aware of my inexperience. I was unsure how much information to extrapolate and how to name themes. My initial feedback was that I was too categorical with the theme titles and I should make these themes titles more meaningful for the

women. I had to go back to the three transcripts that I had analysed and try to keep to the meaning as much as possible in the process. I also had to ensure that I did not derive interpretations that were not evident within the text. This was another process whereby I had to suppress my clinical 'hat' in favor of my research 'hat'.

In writing up the research I found it was difficult to really compact down what the women said into the results section. I did not want to do the women a disservice by not including their quotes. I became emotionally attached to their words and could not delete them. In the end I had to leave the results section until I reached a point whereupon I had to be ruthless and start deleting.

## **MAINTAINING MOTIVATION AND PROBLEM RESOLUTION**

Throughout this process, I think that one of the most difficult aspects has been managing the stress of the project. Both my partner and myself were finishing our doctoral theses at the same time at the same University. Thus, we had the same deadline and due to various unexpected reasons we had the same study blocks. Our house was no longer a place where we could retreat to and find sanctuary. As a result, the process became even more overwhelming and all encompassing. The resolution for this was finding separate places to work, having a strong relationship, a good social network and finding time to relax.

I found it very difficult to juggle my clinical work, other academic projects and the demands of the research as they were all important and required time and effort. Fortunately, my placement supervisors were very supportive and sympathetic to my situation and helped me plan my caseload around non-

demanding times. Furthermore, I anticipated that I needed to focus my study leave not only around my planned deadlines, but also to structure it in a way that best suited my needs, for example, to have longer study blocks. This enabled me to immerse myself in the process, rather than having study time that felt scattered and fragmented.

I always had motivation for the research project. I was genuinely interested in the research area and thoroughly enjoyed interviewing the women, analysing the data and writing it up. On the other hand, finding motivation to complete the literature review was very difficult. I found it dry, tedious and lacking passion. Furthermore, I had decided to focus on my analysis before completing the literature review and the pressure was mounting which may have impaired my enthusiasm. The only way that I could achieve motivation was reducing the review into small and achievable chunks. This way, the task did not seem so daunting and was quickly achieved.

During the research I have had two NHS supervisors. When my first supervisor told me that she was due to go on maternity leave at the time when I would be analysing all the data, I felt quite concerned. This supervisor was very skilled in IPA, and I was counting on her expertise to make up for the lack of mine. However, she placed much thought into finding another NHS supervisor for the project; someone who also had experience in qualitative methodology. I had initial concerns that both my new NHS supervisor and my academic supervisor may have conflicting supervisory styles. However, for myself as a supervisee, I felt that the two different styles of supervision were helpful and gave me

direction, targets to work towards, advice, confidence, and the support I needed, especially as life was tough at home.

### **WHAT WAS LEARNT ABOUT THE RESEARCH PROCESS AND HOW IT MIGHT INFORM FUTURE PRACTICE?**

I really enjoyed the process of undertaking qualitative research and it has revived my interest in research. As a direct result of this project I intend to undertake further qualitative research. I see the merit in undertaking qualitative methodology in addition to quantitative methods as it can add depth to the analyses. Certainly in a complex subject such as sexuality, it is difficult to tease out all the interrelationships between the variables that determine sexual satisfaction. However, to a certain extent qualitative research allows us to do this. The current project has increased my knowledge of qualitative methodology and has enabled me to be more critical when reading qualitative research articles. I believe that within psychology, qualitative research is still in its infancy.

For my clinical practice, it has highlighted the need for systemic therapy within genito-urinary medicine. Much of the research in this area and certainly what I found from my interviews clearly demonstrated that factors outside of the person are as influential as interpersonal factors in sexual health. However, many of the people who attend our service come alone and we see very few couples. How to encourage partners to attend is something that I will think about in my clinical practice.

# APPENDICES

## **Appendix 1**

### **Notes for contributors for the British Journal of Health Psychology**



Search the website:

## Notes for Contributors

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The following types of paper are invited:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology;
- methodological papers dealing with methodological issues of particular relevance to health psychology.

### 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

### 2. Length

Papers should normally be no more than 5,000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

### 3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

### 4. Online submission process

- 1) All manuscripts must be submitted online at

**First-time users:** click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

**Registered users:** click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

- 2) Follow the step-by-step instructions to submit your manuscript.

The Psychologist  
Division / Section Publications  
Consultation Papers

#### Journals

- British Journal of Psychology
- British Journal of Clinical Psychology
- Psychology and Psychotherapy: Theory, Research and Practice
- ↓ British Journal of Health Psychology
  - Online Articles
  - Order Information
  - Journal Scope
  - Editorial Board
  - **Notes for Contributors**
- British Journal of Educational Psychology
- British Journal of Developmental Psychology
- British Journal of Social Psychology
- British Journal of Mathematical and Statistical Psychology
- Legal and Criminological Psychology
- Journal of Occupational and Organizational Psychology
- Subscribe Online
- Why Subscribe to our Journals
- Online submission and peer review
- Principles of Publishing
- Author Resources
- Abstracted in (Secondary Sources)
- Reviews of Your Publications in Our Journals
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- Permission Request Form
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- [Back-volumes and back-issues](#)

Position Papers

Working Party Reports

Research Digest

Proceedings


Information for the Public


The Appointments Memorandum

Undergraduate Course

Accreditation Documents


3) The submission must include the following as separate files:

- Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author -  [Editorial Manager Title Page for Manuscript Submission](#)
- Abstract
- Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors -  [Editorial Manager - Tutorial for Authors](#)



Authors can log on at any time to check the status of the manuscript.

## 5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi.
- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions -  [British Journal of Health Psychology - Structured Abstracts Information](#)
- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA

## 6. Publication ethics

Code of Conduct -  [Code of Conduct, Ethical Principles and Guidelines Principles of Publishing](#) -  [Principle of Publishing](#)

## 7. Supplementary data

Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

## 8. Post acceptance

PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication for easy and cost-effective dissemination to colleagues.



## 9. Copyright

To protect authors and journals against unauthorised reproduction of articles, The British Psychological Society requires copyright to be assigned to itself as publisher, on the express condition that authors may use their own material at any time without permission. On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form.

## 10. Checklist of requirements

- Abstract (100-200 words)
- Title page (include title, authors' names, affiliations, full contact details)
- Full article text (double-spaced with numbered pages and anonymised)
- References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs.
- Tables, figures, captions placed at the end of the article or attached as separate files.

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## **Appendix 2**

### **Letter of approval from Chair of the Research Subcommittee, Clinical Psychology Unit, University of Sheffield**



# THE UNIVERSITY OF SHEFFIELD

## Clinical Psychology Unit

### Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
Clinical supervision training and NHS research training and consultancy

**Clinical Psychology Unit**  
**Department of Psychology**  
**University of Sheffield**

Telephone:  
Fax:  
Email:

Unit Director: Prof Graham Turpin  
Assistant Director : Prof Pauline Slade  
Prof Gillian Hardy

Clinical Practice Director: Ms Joyce Scaife  
Course Administrator: Carole Gillespie  
Prof Nigel Beail

---

24<sup>th</sup> March 2005

Laura Birnie  
Third year trainee  
Clinical Psychology Unit  
University of Sheffield

Dear Laura

I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

**Literature Review:** British Journal of Health Psychology

**Research Report:** Option A

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely

Jason Davies  
Research Tutor

## **Appendix 3**

### **Letter confirming ethical approval from South Sheffield Research Ethics Committee**

## South Sheffield Research Ethics Committee

### South Sheffield Ethics Office

307 Western Bank  
Sheffield

Telephone:

Email:

Chair: Dr. M Hatton

Acting Administrator: Ms. L. Horne

Professor Pauline Slade  
Assistant Director Clinical Psychology Unit  
Clinical Psychology Unit  
University of Sheffield

Dear Professor Slade

**Full title of study:** Living with multiple sclerosis: Women's experiences of sexuality and intimate relationships.

**REC reference number:** 04/Q2305/111

Thank you for your letter of 26/11/04, responding to the Committee's request for further information on the above research and submitting revised documentation

The further information has been considered on behalf of the Committee by the Chair.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed that they have no objection.

### Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application	3.0	25/08/2004	07/09/2004
Investigator CV	1.0	25/08/2004	07/09/2004
Protocol	1.0	23/08/2004	07/09/2004
Covering Letter	1.0	06/09/2004	07/09/2004

Peer Review	1.0	13/04/2004	07/09/2004
Interview Schedules/Topic Guides	1.0	23/08/2004	07/09/2004
Copy of Questionnaire	2.0	23/08/2004	07/09/2004
Letters of Invitation to Participants	1.0	23/08/2004	07/09/2004
Participant Information Sheet	1.0	23/08/2004	07/09/2004
Participant Consent Form	1.0	23/08/2004	07/09/2004
Response to Request for Further Information <ul style="list-style-type: none"><li>• PIS, SSREC V2</li></ul>			26/11/2004
Other		23/08/2004	07/09/2004

### Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

### Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

04/Q2305/111

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely,

pp Dr. M Hatton  
Chair

Enc Approval Conditions

CC Laura Bimie



# Central Office for Research Ethics Committees (COREC)

## RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

### Standard conditions of approval by Research Ethics Committees

1. Further communications with the Research Ethics Committee
  - 1.1 Further communications during the trial with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.
2. Commencement of the research
  - 2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.
  - 2.2 In the case of multi-site research requiring site-specific assessment, the research may not commence at any site until the Committee has notified the Chief Investigator that there is no objection from the relevant Local Research Ethics Committee or other approved local assessor.
  - 2.3 The research may not commence at any site until the local Principal Investigator or research collaborator has obtained management approval from the relevant host organisation.
  - 2.4 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay. It is open to the Committee to allow a further period of 12 months within which the research must commence.
  - 2.5 Should the research not commence within 24 months, the favourable opinion will be suspended and the application would need to be re-submitted for ethical review.
3. Duration of ethical approval
  - 3.1 The favourable ethical opinion for the research applies for the expected duration of the research as specified in the application form. If it is proposed to extend the duration of the study, this should be submitted for approval as a substantial amendment.

#### 4. Progress reports

- 4.1 Research Ethics Committees are required to monitor research with a favourable opinion. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.
- 4.2 Progress reports should be in the format prescribed by COREC and published on the website (see [www.corec.org.uk](http://www.corec.org.uk)).
- 4.3 Progress reports should include an annual list of any Serious Adverse Events occurring to research subjects (see paragraph 8.3 below).
- 4.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

#### 5. Amendments

- 5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.
- 5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:
  - (a) the safety or physical or mental integrity of the trial participants
  - (b) the scientific value of the trial
  - (c) the conduct or management of the trial.
- 5.3 Notices of amendment should be in the format prescribed by COREC and published on the website, and should be personally signed by the Chief Investigator.
- 5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the trial are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.
- 5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

#### 6. Changes to sites (*multi-site studies requiring site-specific assessment only*)

- 6.1 Where it is proposed to include a new site in the research, there is no requirement to submit a notice of amendment form to the Committee. Part C of the application form together with the Principal Investigator's CV should be submitted to the relevant LREC for site-specific assessment. If no objection is notified, the Committee will extend the favourable ethical opinion to the new site.
- 6.2 Similarly, where it is proposed to make important changes in the management of a site (in particular, the appointment of a new Principal Investigator), a notice of amendment form is not required. A revised Part C for the site (together with the CV



for the new Principal Investigator if applicable) should be submitted to the relevant LREC for site-specific assessment.

## **7. Urgent safety measures**

- 7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.
- 7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action. Notifications should be in the format prescribed by COREC and published on the website.

## **8. Serious Adverse Events**

- 8.1 Any Serious Adverse Event (SAE) occurring to a research subject must be promptly notified to the Committee where it is considered possible that the event resulted from their participation in the research. An SAE is an untoward occurrence that:
- (a) results in death
  - (b) is life-threatening
  - (c) requires hospitalisation or prolongation of existing hospitalisation
  - (d) results in persistent or significant disability or incapacity
  - (e) consists of a congenital anomaly or birth defect
  - (f) is otherwise considered medically significant by the investigator.
- 8.2 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by COREC and published on the website.
- 8.3 An annual list of SAEs occurring in the research should be provided to the Committee with the annual progress report.
- 8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.
- 8.5 There is no requirement to provide reports to other RECs in the case of multi-site studies.

## **9. Conclusion or early termination of the trial**

- 9.1 The Chief Investigator should notify the Committee in writing that the trial has ended, and provide a final report on the research, within 90 days of the conclusion of the research. The conclusion of the trial is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.
- 9.2 If the trial is terminated early, the Chief Investigator should notify the Committee within 30 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Final reports, or reports of early termination, should be submitted in the form prescribed by COREC and published on the website.

10. Breach of approval conditions

10.1 Failure to comply with these conditions may lead to suspension or termination of the favourable ethical opinion by the Committee.

## **Appendix 4**

### **Letter of invitation to participants**

**THE UNIVERSITY OF SHEFFIELD**

**Clinical Psychology Unit**

**Department of Psychology**

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
Clinical supervision training and NHS research training and consultancy



**Clinical Psychology Unit**  
**Department of Psychology**  
**University of Sheffield**

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Unit Director: Prof Graham Turpin  
Assistant Director : Prof Pauline Slade  
Prof Gillian Hardy

Clinical Practice Director: Ms Joyce Scaife  
Course Administrator: Carole Gillespie  
Prof Nigel Beail

4<sup>th</sup> Jan 2005

Dear

My name is Laura Birnie and I am a Trainee Clinical Psychologist at the University of Sheffield. I am writing to invite you to take part in a study that I am undertaking which examines the experiences of women with Multiple Sclerosis. I have asked staff from the MS team (Royal Hallamshire Hospital) to identify any women in their service who may be interested in taking part in the study. This study is supported by the Multiple Sclerosis Team and is being conducted with the assistance of Diane Watts (MS Team Leader).

Research has shown that MS can affect people's sexual and intimate lives in different and often important ways. However, much of this research is based on how often it occurs and very little is known about what this *means* to people, especially younger women. I would like to spend time with women discussing their experiences of sexuality and intimate relationships whilst living with MS. I hope that the information gained from the research will help us to better understand how MS may impact upon women's sexual and intimate lives, and help inform the way health professionals think about these issues.

I have enclosed an information sheet that describes the study in more detail and I hope this will answer any questions you may have. If you have any further questions then please do not hesitate to contact me at the University of Sheffield on (0114) 222 6570.

If you are interested in taking part, please complete and return the reply slip in the envelope provided by 20<sup>th</sup> February 2005.

Yours sincerely,

Laura Birnie  
Psychologist in Clinical Training

## **Appendix 5**

### **Participant Information Sheet**

**THE UNIVERSITY OF SHEFFIELD**
**Clinical Psychology Unit**
**Department of Psychology**

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
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Clinical Practice Director: Ms Joyce Scaife  
Course Administrator: Carole Gillespie  
Prof Nigel Beal

**RESEARCH INFORMATION SHEET**
**Living with Multiple Sclerosis: Women's experiences of sexuality and intimate relationships.**

My name is Laura Birnie. I am a Trainee Clinical Psychologist at the University of Sheffield. I am working with staff from the Multiple Sclerosis team at the Royal Hallamshire Hospital to undertake a study. This is to listen to people's experiences of living with Multiple Sclerosis (MS). I have asked staff from the MS team to identify any women in their service who may be interested in taking part in the study. This research is being completed as part of my Doctorate in Clinical Psychology.

**What is the study about?**

Research has shown that MS can affect people's sexual and intimate lives in different and often important ways. Yet very little is known about what this *means* to people, especially young women. I would like to spend some time with women exploring their views on sexuality and intimate relationships with regard to their MS. I hope the information gained from this research will help us to understand better the impact of sexual difficulties on women with MS, and help inform the way health professionals think about these issues.

**Who will be taking part?**

About 10-12 women will be interviewed. You will need to be aged between 20-35, and have been diagnosed with MS by a consultant neurologist for at least two years. You do not need to be in a relationship to participate in the interview.

**If I take part, what does it involve?**

You will be asked to complete a consent form and one very short questionnaire regarding your physical health status and your emotional wellbeing. The interview will last approximately 1-1½ hours. We will discuss how your life has changed because of the MS. This will involve specific discussions on intimate and sexual relationships, perhaps with your past and / or current partner. This will also mean talking about how you view your own sexuality. Some of the questions may be quite sensitive but you do not have to discuss anything that you do not want to.

**Will the interview be confidential?**

Yes, the research will be kept confidential to myself and my supervisors (Dr. Maria Jarman and Prof. Pauline Slade). I will anonymise the data, and any reference to particular people or places. The interview will be tape-recorded but the audio-tapes will be stored securely, and destroyed after the research has been completed. In the final report, short extracts from conversations will be included which will be totally anonymous.

**When and where will the interview take place**

You can be interviewed in your own home, or in a meeting room at the Royal Hallamshire Hospital. If you would like to take part but you can't be interviewed at home this can be discussed. Any travel expenses will be reimbursed.

**What if I want further support about some of the issues I discussed in the interview?**

For some women, difficult or distressing thoughts or feelings may be highlighted in the interview. If you wish to speak to someone about any of the issues we discussed in the interview then please contact your MS nurse. If you feel unable to do this, then I can contact him/her on your behalf.

**Can I pull out from the study at any time?**

You are within your rights to stop participating from the interview at any time, even if the interview has started. This will not affect any treatment you receive from the MS service.

**What if I am harmed?**

If you are harmed by your participation in this study, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**Who will provide indemnity for the research?**

Indemnity for this research has been given by Sheffield Teaching Hospital NHS Foundation Trust and the University of Sheffield.

**Who do I talk to if I wish to complain about the study?**

If you have any cause to complain about any aspect of the way you have been approached or treated during the course of the study, the normal National Health Service complaints mechanisms are available to you. You are not compromised in any way because you have taken part in a research study. If you have any complaints or concerns people should contact the project co-ordinator (Prof. Pauline Slade, Clinical Psychology Unit, University of Sheffield on \_\_\_\_\_ or Dr. Maria Jarman (NHS Supervisor, Royal Hallamshire Hospital on \_\_\_\_\_ in the first instance. If this is not satisfactory, you can also use the normal hospital complaints procedure through Sheffield Teaching Hospital (Dr. Chris Welsh, Medical Director on \_\_\_\_\_

**If you would like any more information, please contact me at the University of Sheffield on \_\_\_\_\_**

**Thank-you for reading this information sheet**

## **Appendix 6**

### **Consent to be contacted form**





**THE UNIVERSITY OF SHEFFIELD**

**Clinical Psychology Unit**

**Department of Psychology**

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
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Prof Gillian Hardy

Clinical Practice Director: Ms Joyce Scaife  
Course Administrator: Carole Gillespie  
Prof Nigel Beail

**CONSENT TO BE CONTACTED**

**Research title:** Living with Multiple Sclerosis: Women's experiences of sexuality and intimate relationships.

**Researcher:** Laura Birnie, Trainee Clinical Psychologist,  
University of Sheffield.

***To be completed by you***

Name .....

Address .....

.....

Mobile number .....

Home number .....

Email address .....  
(if preferred)

**I would like to be contacted by the researcher to discuss the study further.**

Signature.....

## **Appendix 7**

### **Consent to participate form**

## THE UNIVERSITY OF SHEFFIELD

### Clinical Psychology Unit

### Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)  
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Course Administrator: Carole Gillespie  
Prof Nigel Beail

## CONSENT FORM

Please  
initial box

I have read and understood the participant information sheet

I have had the opportunity to ask any questions about the study, and I am happy with the answers given.

I understand that I am free to withdraw from the study at any time without having to provide a reason.

I understand that the interview will be tape-recorded. The tape will be destroyed when the research is completed.

I understand that any written or published information related to this study will be completely anonymous.

I agree to take part in this study.

Signed..... Date...../...../.....

Name (in block letters).....

I witness that I have provided the above with the appropriate information. I believe the consent given above was an informed decision, and freely given.

Signed..... Date...../...../.....

Name (in block letters).....



## **Appendix 8**

### **Quality of Life measure (SF-26)**

# HEALTH STATUS QUESTIONNAIRE (SF-36v2)

The following questions ask you about your health, how you feel and how well you are able to do your usual activities.

If you are unsure how to answer a question, please give the best answer you can.

## OVERALL HEALTH

1. In general, would you say your health is:

*(Please circle one number only)*

Excellent..... 1  
Very good ..... 2  
Good ..... 3  
Fair ..... 4  
Poor..... 5

2. Compared to one year ago, how would you rate your health in general now?

*(Please circle one number only)*

Much better now than one year ago ..... 1  
Somewhat better now than one year ago..... 2  
About the same as one year ago..... 3  
Somewhat worse now than one year ago.. 4  
Much worse now than one year ago ..... 5

*Please turn the page and continue*

## HEALTH AND DAILY ACTIVITIES

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

*(Please circle one number on each line)*

ACTIVITIES	Yes, limited a lot	Yes, limited a little	No, not limited at all
a. <b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing <b>several</b> flights of stairs	1	2	3
e. Climbing <b>one</b> flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking <b>more than a mile</b>	1	2	3
h. Walking <b>several hundred yards</b>	1	2	3
i. Walking <b>one hundred yards</b>	1	2	3
j. Bathing or dressing yourself	1	2	3

***Please turn the page and continue***

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

*(Please circle one number on each line)*

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	1	2	3	4	5
b. Accomplished less than you would like	1	2	3	4	5
c. Were limited in the kind of work or other activities	1	2	3	4	5
d. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2	3	4	5

5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

*(Please circle one number on each line)*

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Cut down on the amount of time you spent on work or other activities	1	2	3	4	5
b. Accomplished less than you would like	1	2	3	4	5
c. Did work or other activities less carefully than usual	1	2	3	4	5

**Please turn the page and continue**

**6. During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?**

*(Please circle one number)*

- Not at all..... 1
- Slightly..... 2
- Moderately ..... 3
- Quite a bit..... 4
- Extremely ..... 5

**7. How much bodily pain have you had during the past 4 weeks?**

*(Please circle one number)*

- None ..... 1
- Very mild ..... 2
- Mild ..... 3
- Moderate..... 4
- Severe..... 5
- Very severe..... 6

**8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

*(Please circle one number)*

- Not at all..... 1
- A little bit..... 2
- Moderately ..... 3
- Quite a bit..... 4
- Extremely ..... 5

**Please turn the page and continue**



## YOUR FEELINGS

9. These questions are about how you feel and how things have been with you during the past 4 weeks. (For each question, please give the one answer that comes closest to the way you have been feeling.)

*(Please circle one number on each line)*

How much of the time during the <u>past 4 weeks</u> :	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5
b. Have you been very nervous?	1	2	3	4	5
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5
d. Have you felt calm and peaceful?	1	2	3	4	5
e. Did you have a lot of energy?	1	2	3	4	5
f. Have you felt down-hearted and depressed?	1	2	3	4	5
g. Did you feel worn-out?	1	2	3	4	5
h. Have you been happy?	1	2	3	4	5
i. Did you feel tired?	1	2	3	4	5

***Please turn the page and continue***

## HEALTH IN GENERAL

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)?

(Please circle one number)

- All of the time ..... 1  
Most of the time ..... 2  
Some of the time ..... 3  
A little of the time ..... 4  
None of the time ..... 5

11. How TRUE or FALSE is each of the following statements for you?

(Please circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!**

## **Appendix 9**

### **Interview Schedule**

## INTERVIEW SCHEDULE

### Introduction

1. **Can you tell me about when you found out you had Multiple Sclerosis?**

*How did you find out? How long ago? Who told you? How did you feel?*

### Intimate relationships

2. **Were you in a relationship at the time you were diagnosed with MS?**

*Can you tell me about this relationship? How did your partner/s find out? What was it like? How did your partner respond?*

3. **Can you tell me about any brief or long-term intimate or partner relationships you have had since you have been diagnosed with Multiple Sclerosis?**

*How would you describe this/these relationship/s? Has anything changed for the better or worse?*

*Can you give examples? (Emotions? Feelings? Thoughts?)*

4. **How would you describe your sexual relationship/s since your diagnosis of MS?**

*How would you describe your sexual relationship before the illness or diagnosis?*

*Is anything different now? Is anything the same? - Has having MS changed your sexual relationship?*

5. **Since you have been diagnosed with multiple sclerosis, what have been the good and not so good aspects of having sex?**

### SEXUALITY

6. **How would you describe your relationship with your body since your diagnoses of MS?**

*How did you think about, or view your body before the MS? How do you think about, or view your body now? Have things changed, in what way, better / worse?*

7. **How do you feel about yourself as a sexual woman?**

*How do you express your sexuality or sexual identity? How do you express yourself in a sexual way?*

### Endings

**8. What has been the most important thing we have discussed?**

**9. Is there anything that we haven't spoken about that you thought we would talk about today?**

**10. Before we finish this interview, are there any questions that you would like to ask me?**

## **Appendix 10**

### **Confidentiality form for transcriber**



**THE UNIVERSITY OF SHEFFIELD**  
**Clinical Psychology Unit**  
**Department of Psychology**

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Course Administrator: Carole Gillespie  
Prof Nigel Beail

**CONFIDENTIALITY FORM FOR TRANSCRIBERS**

**Research title:** Living with Multiple Sclerosis: Women's experiences of sexuality and intimate relationships.

**Researcher:** Laura Birnie, Trainee Clinical Psychologist

The tape you are transcribing has been collected as part of a research project. The tapes will contain information that is very personal and sensitive to the women involved. This information should be kept confidential **and not disclosed to others**. Maintaining this confidentiality is of utmost importance to myself, the University and to the interviewees.

We would like you to agree not to disclose any information you may hear on the tape to others, to keep the tape in a secure place where it **can not** be heard by other people, and only show your transcription to the relevant individual who is involved in the research project. If you find that anyone speaking on a tape is known to you, we would like you to stop transcription work on that tape **immediately**.

**Declaration**

I understand that:

1. I will discuss the content of the tape only with the individual involved in the research project.
2. I will keep the tape in a secure place where it cannot be heard by other
3. I will treat the transcription of the tape as confidential information
4. If the person being interviewed on the tapes is known to me, I will undertake no further transcription work on the tape.

*I agree to act according to the above constraints*

Your name \_\_\_\_\_

Date \_\_\_\_\_

Your signature \_\_\_\_\_

Date \_\_\_\_\_

## **Appendix 11**

### **Transcription criteria**



## INSTRUCTIONS FOR TRANSCRIBERS

**Research title:** Living with Multiple Sclerosis: Women's experiences of sexuality and intimate relationships.

**Researcher:** Laura Birnie, Trainee Clinical Psychologist

Before transcribing the interview, please read the following information.

---

*Please ensure that:*

- You type *exactly* what was said and do not impose meanings onto the text. This is extremely important.
- You ensure that the transcript is anonymous. The interviewees will have a number which should be written on the top left of the every page.
- Leave margins of 4cm on both the left and the right side of the page
- There is a space between the lines
- Each line is numbered
- Each page is numbered
- Pauses over 3 seconds to be denoted as ...
- Indicate who is speaking. The researcher as 'R' and the participant as 'P'.
- The researchers text is typed in *italics*.

**Thank-you for reading this**

## **Appendix 12**

### **Audit trail (Example of Interpretative Phenomenology Analysis)**

## An illustrated account of the IPA process

### **1. Analysis of individual participant's accounts: transcript to early thoughts:**

During this stage, each individual transcripts are read many times to identify points of interest and significant quotes (Smith et al, 1999). In the following example, Kate is talking about her sexual relationship. With the use of a research diary to aid reflexivity (Elliot et al, 1999), it was observed that during most of this interview, including here, Kate was tearful, although this is not apparent from the transcript.

*Impact of MS symptoms*  
*Re-prioritisation of sex*  
*Flexibility, making time to*  
*be intimate,*  
*Sex being fun,*

*Creativity, not restricted by*  
*MS? Problem solving*

*Planning times around MS*  
*Personal importance of*  
*intimacy, meaning of sex-*  
*closeness*  
*Uncertainty over future*  
*symptoms: 'giving it up',*  
*MS progression: anticipated*  
*difficulties (tearful)*

*Impact of physical*  
*symptoms on sex:*  
*reluctance*

**P:** Yeah, I mean it's like with fatigue, it's like sometimes at night, oh, you just want to be quiet and that so, maybe looking at other times, maybe in the day and I, I know when [child's] at school that's, that's quite fun really (laughter) if [partner] has a day off because he works shifts, you know, and, so it, it's about being, you're not, you've just got to be a little bit more creative really and, and think of ways round it, okay evenings might not, or nights might not be a good time to have, to make love so you, you think, oh I'll do it in the morning or, or whatever, it's important to me to have that closeness and that intimacy, and I can't even, ever imagine not, or giving that up whatever, so, and in, probably the times in the future where it might be challenged a bit more but I, it's, not really for now, the only time I never really feel like making love is when I've had numbness and I've had numbness which has affected all my body including my vagina and things, and –

## **2. Analysis of individual participant's accounts: from quotes to the individual's**

**themes:** In this second stage, pertinent emerging themes are written in the right margin (see below).

- P:** Yeah, I mean it's like with fatigue, it's like sometimes at night, oh, you just want to be quiet and that so, maybe looking at other times, maybe in the day and I, I know when my [child's] at school that's, that's quite fun really (laughter) if [partner] has a day off because he works shifts, you know, and, so it, it's about being, you're not, you've just got to be a little bit more creative really and, and think of ways round it okay, evenings might not, or nights might not be a good time to have, to make love so you, you think, oh I'll do it in the morning or, or whatever, it's important to me to have that closeness and that intimacy, and I can't even, ever imagine not, or giving that up whatever, so, and in, probably the times in the future where it might be challenged a bit more but I, it's, not really for now, the only time I never really feel like making love is when I've had numbness and I've had numbness which has affected all my body including my vagina and things, and –
- Reframing restrictions as something positive*
- Flexibility with time*
- Being creative: thinking ways around the fatigue*
- Sex: involves closeness and intimacy*
- Uncertainty of future symptoms*

### 3. Analysis of individual participant's accounts: collating the themes

Following from stage two, all the themes and their supporting quotes are cut and pasted into a new word document and sorted into thematic clusters as demonstrated:

	Line No.	Quotes	Initial themes
Initial clusters	604	looking at other times, maybe in the day and I, I know when my [child's] at school that's, that's quite fun really	<i>Reframing restrictions as something positive</i>
	604	looking at other times, maybe in the day and I, I know when my [child's] at school that's, that's quite fun really	<i>Sex as fun</i>
	612	it's important to me to have that closeness and that intimacy, and I can't even, ever imagi612_ne not, or giving that up whatever,	<i>Sex: involves closeness and intimacy</i>
Initial clusters	604	looking at other times, maybe in the day and I, I know when my [child's] at school that's, that's quite fun really	<i>Flexibility with time</i>
	608	you've just got to be a little bit more creative really and, and think of ways round it okay	<i>Being creative: thinking ways around the fatigue</i>
	614	probably the times in the future where it might be challenged a bit more but I, it's, not really for now	<i>Uncertainty of future symptoms: anticipated difficulties</i>
	616	the only time I never really feel like making love is when I've had numbness and I've had numbness which has affected all my body including my vagina and things, and	<i>Impact of MS symptoms on sex: reduced reluctance</i>

#### **4. Analysis of individual participant's accounts: identifying thematic clusters**

Once the whole transcript had been organised in this way, preliminary groups were generated for each participant. As the analysis progressed, some themes were dropped where there was limited supporting evidence. Some themes were relevant as both a super-ordinate theme and a sub-ordinate theme (i.e. sex facilitating relationship security and the relationship sexuality facilitating good sex). These were placed wherever relevant to assist later cross-examination of themes. During all stages of analysis pertinent quotes and themes were kept together to prevent any potential and unintentional divergence from the original meanings. The initial super-ordinate list of themes for Kate were as follows:

##### **Making changes**

Life priorities (439)  
Reframing potential negatives into a positive (134)  
Evolution in relationship (326)  
Within sexual relationship (696)  
How views herself (214)

##### **Security in partner relationship**

Relationship security fostered by history of relationship (377)  
Feeling supported (845)  
Partner not leaving (255)  
Communication and honesty (749)  
Being with Kate despite the MS, not because of it (247)  
Facilitated good sex (387)  
Security bolsters body-image

##### **Retaining self-esteem**

Acknowledging strengths (347)  
Dismissing societal expectations (758)

##### **Sex and intimacy**

Facilitate security in relationship (671)  
Demonstrated equity (701)  
Closeness (612)

##### **Making an effort in sexual relationship**

Being creative, being flexible (609)  
Reflects levels of trust in partner relationship (592)  
Prioritising sex despite (566)

##### **Living with uncertainty**

Can't see future (108)  
Need to reframe uncertainty (137)  
Unable to predict or plan (94)

##### **Relationship with disability**

Feeling different (986)  
Being treated differently (159)  
Conflicts between not looking ill and feeling ill

##### **Feeling misunderstood and unaccepted**

Loss of Friends (262)  
Feeling lonely (1033)  
Conflict between others expectations of her and how she presents to the world (759)  
Lack of acceptance (lack of empathy) (1002)

## **5. Identification of shared themes across the participants**

In the next stage of analysis, the super-ordinate list of themes generated for each participant was cross-examined to identify shared themes across the group of interviewees. This process was facilitated by photocopying each interviewee's list of super-ordinate themes, cutting them onto separate pieces of paper and arranging them on a large workspace. This process enabled the data to be simultaneously appraised, which allowed new groupings to emerge. Finally, four super-ordinate themes, comprising ten sub-ordinate themes were identified as being shared by six or more women:

### **A) Issues relating to how the women manage adversity**

- 1) Living with "definite" uncertainty
- 2) Reframing adversity

### **B) The women's relationship with others in the women's social world (feeling different)**

- 1) "I just want to be treated normal": Feeling different
- 2) Comparison with others

### **C) Acceptance from partners (current & past) and others in the women's social world (e.g. society, friends, family, colleagues etc)**

- 1) Acceptance by others
- 2) "Getting in or staying out": Partner acceptance
- 3) Fitting MS into the relationship

### **D) The meaning of sex and the many influences upon this.**

- 1) The meaning of sex
- 2) Making the effort for sex and sexiness
- 3) Sexual difficulties within the context of the wider relationship