

Thesis title: What are the personal and health care experiences of women with MS?

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Declaration

I declare that the content of this thesis is all my own work and I take full responsibility as the author.

Abstract

Multiple Sclerosis (MS) is a neurological condition with current statistics highlighting that, worldwide, women predominantly experience its impact at a rate of 4:1 (Jelinek, 2010). There are currently no medical cures for the illness and people can become extremely physically disabled (Kalb, 2005). This research explores the lived experiences of women who have a diagnosis of MS and the primary data in this research were collected during semi-structured interviews with 16 of them aged between 21 to 71 years old. The research methodology chosen draws on feminist influences for the framework of the research design whilst also being influenced by narrative perspectives of data collection methods and analysis. The research is described as being a qualitative feminist narrative study. As someone who has a diagnosis of MS this thesis also draws on my own self-ethnography and experiential knowledge. The data were analysed using thematic and narrative analysis. The findings highlighted that the presentation of MS symptoms to GPs were not initially recognised and that a process of mis diagnosis occurred in the majority of cases for a significant period of time with up to 27 years being reported in this study. Further findings indicated that the women in this study were not all provided with choices, options and relevant information in relation to MS. The detailed narratives from the women about their experiences with MS highlighted a journey of personal development and insight into living and adjusting to the symptoms of a chronic illness. The women also offer their own interpretations about the onset of their MS symptoms.

Section 1: Defining the theoretical perspectives for investigating MS and women

Section 1 of the thesis contains the background work of the research topic, the review and focus of literature, methods and methodology, research plan and research questions informing the reader about the focus and attention of the empirical study. Chapter 1 lays out the key perspectives contained within the thesis outlining the structure and the key arguments of the thesis. One of the key arguments contained within the empirical study is that medical regimes and practices shape and control women's bodies through cultural and social attachments (as highlighted in Chapter 1, section 1.6). This argument is applied and further investigated drawing on the experiences of women living with MS. Chapter 2 specifically details a review of literature in relation to MS. This chapter contains an exploration of the emergence and identification of MS as a medical neurological disease. Furthermore, some current medical and social perspectives are discussed. Chapter 3 details the relationship between women's bodies and medicine, specifically noting the shaping and controlling of women's bodies within medicine drawing on a feminist perspective. This account of the literature is central for moving forward with a narrative study into the experiences of the women in this empirical study. The juxtaposition of medical and social care perspectives of MS and a discussion of women's bodies and medicine contextualises the research topic of MS and feminist perspectives on the production of women's bodies within medicine.

Chapter 1: Exploring women's experiences of Multiple Sclerosis (MS)

Prologue

This qualitative feminist narrative study has explored the experiences of women living with Multiple Sclerosis (MS) and examined how their lived experiences have been shaped and understood by them over time. The focus of the study was rooted in a feminist methodological research perspective and brings together the current medical definition and understanding of MS drawing on some relevant medical and social care research; a feminist understanding of the experience of women's bodies and how they are culturally and socially shaped together with the lived experience of living with MS for the women who took part in this study. These core components create a dynamic discussion which couches the research focus within the sociology of health and illness.

This introductory chapter outlines and positions the context and perspective for the focus of the thesis question about women's experiences with MS. This first chapter encapsulates the journey of the thesis, carefully piecing together the relevance of each subsequent chapter which form the overall thesis. My own experience of living with MS offered a parallel trajectory and enabled a shared context to develop, accepting that each of the women had their own experienced journey to share.

Introduction

First, in this chapter the author shares with the reader her real life experiences that were a strong part of the motivation to undertake a PhD. Second some information about MS is presented; this includes recognised symptoms and clinical classifications. Third there is an exploration of the research questions, which leads to a statement of the aims and objectives of the thesis. Finally, the structure of the thesis content is outlined with a brief summary of the contents of each chapter.

1.1 My life and MS

(Authors Note: This section is written in the first person due to the experiential nature of the discussion).

The genesis for this thesis was rooted in my own first hand experiences with ill health. I was diagnosed with MS when I was 25 years old, although I had experienced MS symptoms since I was 16. From the age of 16 to my diagnosis at the age of 25, I had visited doctors' surgeries to get some help for my symptoms, but I was consistently dismissed in these encounters. It was only after I experienced a more serious health problem (a subarachnoid haemorrhage at the age of 24) that I felt that doctors' took notice of what I was saying. Even then it took a long process over 18 months to get a diagnosis of MS and for me to start realising that it wasn't just my imagination. This was a key turning point in my life as it allowed me to reflect on what had happened since I was 16 years old and the MS symptoms had started. The distress I felt about experiencing these 'health problems', yet having no way to communicate them effectively, had taken its toll on me. I had developed my own internal coping mechanisms to deal with the symptoms when they occurred. For example, if I had blurred vision and dizziness, which I used to experience frequently when I was a late

teenager, I would close my eyes and count to 10 to stop myself from panicking. I have since discovered these are learned coping strategies offered to people who experience panic attacks.

My confidence had been shattered with life circumstances and the experience of MS symptoms which very few people took seriously. Such that when I experienced a horrendous headache (aged 24) that turned out to be a subarachnoid haemorrhage, I sat in a queue of people at the out of hour's doctors' surgery for almost an hour waiting for treatment. This was after I had been turned away from accident and emergency (A&E) at the local hospital because the charge sister said I looked distressed and asked if I was usually this highly strung. She actually enquired whether I had just had an argument with somebody. She suggested that I go home, relax, take 2 paracetamol tablets and go to bed or otherwise I would be waiting over 4 hours to see a doctor. I pleaded with her to allow me to see a doctor as I felt I was going to collapse but she said I was experiencing nothing more than a migraine.

I was overwhelmed with head pain and I described it later as feeling like being hit in the back of the head with a hammer (this had never happened to me but this was how I imagined it to feel). My friend suggested taking me to the out of hour's clinic which was situated in the next town. When we arrived at the clinic it was full mostly of young babies and I remember feeling that it would look terrible if I pushed in demanding to see the doctor. I sat quietly in the queue for almost an hour. When it was eventually my turn to see the doctor I walked into his room and immediately started to projectile vomit. He quickly recognised that I was either experiencing a subarachnoid haemorrhage or meningitis, both of which I then registered as being

serious conditions, and he sent me in an emergency ambulance to the very hospital where I had been rejected from 2 hours earlier. From there I was transferred to a brain specialist unit 30 miles away where I stayed, was treated and spent the next 3 weeks recovering.

I was later told by one of the neurology nurses that had I gone home with the 2 paracetamol and gone to bed as advised by the Charge Nurse I probably wouldn't have survived – I would have been dead instead.

Now, 15 years on at the age of 39, I often have to remind myself that not all people respond to me in a disbelieving and distrustful way. Like many of the women in this study I found, and still find, it difficult to express my experiences and I'm particularly conscious of the fact that people might think I am exaggerating them. Due to this, I often laugh and use humour as a way of expressing pain and explaining distressful personal situations that might sometimes strike the listener as being a little cold or heartless or that my storytelling is prone to gross exaggeration.

The stress of living with MS symptoms, yet not knowing what they were, left me feeling disillusioned with the medical profession. My eventual diagnosis of MS coincided with me studying Sociology as a mature undergraduate student. For my final year dissertation I decided to examine the situation of women, such as myself, with MS. I wondered if I was alone in these experiences. The findings from this qualitative study were based on 10 one to one interviews. The key findings of this small study concluded that:

- MS was a difficult disease to diagnose due to the wide variation in symptoms;
- The difficulty of diagnosing MS due to the wide variation of symptoms translated into doctors applying gendered stereotypes about women on the presentation of MS symptoms;
- Women were often told by doctors that their symptoms of MS were depression and they were treated with anti-depressants and tranquilisers;
- A diagnosis of MS took many years and most of the women I interviewed had waited over 15 years for a diagnosis of MS. This had impacted on their lives and I considered that more research should be conducted to explore these issues.

The findings also indicated that more exploratory research was needed in relation to the realities faced by women living with MS. The research findings suggested that there were key problems with the diagnosis procedures for MS. These findings further suggested that gender and medicine – that is biomedicine – was responsible for these effects. For example, a finding from the study suggested that doctors did not take the women seriously when they presented their MS symptoms. A woman called Gillian who I interviewed told me:

“When I had my first child I started having blurred eyesight and suffered with funny legs. You know what I mean, weak and wobbly, sometimes I thought I was going to fall over. The doctor said that when you have children it changes your body and that’s how he explained it”

Gillian was 63 years old and living with MS when I interviewed her in 2000. Another woman called Delia (aged 55) recalled:

“The specialist and my now ex partner had kept my diagnosis from me for 10 years. I was extremely mad at first but then thought maybe not knowing has helped after all as I’m not in a wheelchair”

As a social researcher I found these accounts disturbing, as a young woman with a diagnosis of MS I found them all too familiar.

From when, I was a teenager I had experienced symptoms I now recognise to be MS, but as a working class woman with a teenage pregnancy, I was often faced with questions related to my ‘sexual lifestyle’ and ‘contraception’. I was sporadically prescribed anti-depressants from the age of 17 until at the age of 24 I collapsed and they had no other option but to investigate my health problems further. The following year I was then diagnosed with MS and within a couple of years was given the opportunity to be put on a treatment plan of innovative self-inject drugs called Copaxone (please see appendix 1 for BNF description) (Please see appendix 1 for BNF description). Gaining access to Copaxone (please see appendix 1 for BNF description)ⁱ gave me hope for the future and enabled me to think about my life again rekindling any ambitions I had. It also made me feel validated within a medical system that had previously only generated an insecurity and cynicism in me.

However, for the older women that I had interviewed there was no hope of being given a chance of any profound treatmentⁱⁱ. When I had interviewed them I could visibly see their disabilities and it had affected me. I felt angry and hurt that the power of medical authority was so dismissive of women’s bodies and their stories stayed with me. What bothered me most of all was the level of acceptance these women had about their bodies and their disabilities. To be clear, I am not suggesting that disability

is negative. What I am suggesting, however, is that these women I interviewed and their understandings of their bodies were bound up with dominant discourses of gender and medicine and they had accepted a biomedical truth about their bodies. For example Ginny outlined:

“Each time I went to see my GP about blurred vision and various numb patches around my body he immediately looked at my menstrual cycle and looked for any problems in my life that could be causing depression. Although I trusted him very much, I sometimes couldn’t really see the relevance. However they do say there is a link between not coping properly and MS, don’t they?”

Each of the women I interviewed had made a comment to me about being a woman and how a lot of things are down to hormones and anxiety because as their doctors had told them, “they do worry an awful lot”. This acceptance of gender and medicine concerned me.

Carrying out this undergraduate study left me with so many questions and challenges surrounding the lives of women with MS. Listening to their stories made me wonder whether they were prisoners of their own bodies, but not because of their disability, but because of the surveillance and control inherent in the biomedical models of diagnoses and treatment regimes. What implications did medical discourse have for these women’s lives, in terms of identity, to adapt to a disabling body? What was the experience of MS really like for them? I remembered how confusing my experience had been when I had displayed symptoms of MS and I was told I was depressed and anxious. I also did have a lot to feel depressed and anxious about as my life trajectory had been disruptive, negative and stressful from my mid to late teens, so I often put my own experiences down to my own issues including low self-esteem. I was shocked to discover that other women had also experienced similar interactions with doctors as

to those I had encountered. In fact, many of the women I have interviewed to date about their occurrences of MS had experienced symptoms of the disease for a period of up to 25 years before they had been diagnosed and again put their ‘strange bodies’ down to anxiety.

So, it is from this point that I started my PhD. Remembering the stories of the older women that I had interviewed, becoming politically aware of my own body through my own experiences with medical authority (and other life experiences), my academic learning, and believing that research should start with people and their experiences in challenging the paradigm in the hierarchy of knowledge making. However, it is important to note that despite the negative encounters with bio-medicine that I and, to some extent, these women I interviewed in my undergraduate study had experienced, that I needed to approach my thesis with an open mind, and ensure that a polemic view was not adopted. For example, in terms of researcher bias during the interview the data collection methods for the study were chosen carefully specifically due to the subjective nature of the research topic. This is outlined in detail in Chapter 4 and specifically in section 4.3. Also, alongside the careful selection of research methods, I had experienced some positive and supportive interactions within medicine. One of the interests I had at the beginning of the study, and throughout the developing study and the end product of a thesis, was to explore the interactions within medicine for people with MS (not seeking to confirm negative encounters for women and MS), and to explore the social relations of medicine, women and the experience of MS. Also, one of the aims of the study was focused around exploring the relationship between women and medicine in a wider, structural context, and not taking a position of defining medicine as having only negative consequences for women.

One key aspect of the data collection process was the understanding I held as a researcher about MS and the symptoms through my own experiences. This enabled me to be sensitive and understanding around some of the descriptions the women held around their health. In order to understand the terminology and the women's experiences it is important to reflect on the physical aspects of the illness. This next section will describe MS and provide the reader with an overview of the symptoms.

1.2 What is MS?

In the UK there are approximately 85,000 people who have a diagnosis of MS (MS Society UK, 2010). Worldwide it has been estimated that there is about 2.5 million people with MS and there is evidence that the disease is appearing more common (Jelinek, 2005). Currently MS is predominant in women with a ratio of 4:1 (MS Society, UK, 2012).

MS is a disease of the central nervous system (CNS). The CNS is a term used to describe the brain and spinal cord (Jelinek, 2005). MS is also classified as an autoimmune disease, which is where the immune system is tricked into believing that its own bodily substances are foreign and starts attacking them (Kalb, 2005).

MS occurs when the immune system attacks the CNS and damages the myelin sheath which is surrounding and covering the nerve fibres (Burgess, 2002). This attack on the nerve fibres within the CNS damages the myelin and strips it off the nerve fibres, either partially or completely, leaving scars also referred to as lesions, plaques or sclerosis (Jelinek, 2005, 2010; Burgess, 2002). This damage to the myelin sheath disrupts the message pathways and the messages can be slowed down, become

distorted, or not get through at all (Perry, 1994). As the CNS links all bodily activities, many different symptoms can appear in MS (MS Society, UK, 2012). The specific symptoms that appear depend on which part of the CNS is affected and the function of the particular damaged nerve. This is the reason why there are so many various symptoms for people with MS.

Main symptoms of MS

MS is an umbrella term that encapsulates a range of symptoms that may be experienced by a person who has MS. Some of the common symptoms:

- Fatigue – an overwhelming sense of tiredness making physical or mental activity extremely difficult;
- Balance problems – walking difficulties, problems with coordination, a feeling of vertigo;
- Visual problems – these can vary from blurred or double vision, temporary loss of sight in one eye or blindness in both eyes;
- Numbness or tingling – commonly in the hands or feet but can occur on any part of the body;
- Pain – occurs anywhere in the body and is sometimes mild, sometimes severe;
- Loss of muscle strength and dexterity;
- Stiffness and spasms – tightening or rigidity in particular muscle groups;
- Emotional problems such as anxiety, depression or mood swings. More recently bi polar disorder has been associated with people with MS;
- Cognitive problems – difficulty with short term and long term memory and concentration;
- Speech problems – slurring, slowing of speech, or changes in pitch or tone;

- Incontinence – a lack of control over bladder or bowel functions.

There are currently 4 categories or types of MS that are used to measure disease progression within medicine. These 4 types are outlined below:

Relapsing remitting MS (RRMS)

Most people are usually first diagnosed with relapsing remitting MS (Burgess, 2002).

RRMS means a flare up of symptoms (also known as an attack or exacerbation) followed by a period of remission. The period of remission may last for a week, a month, a year or a number of years and this is a feature of the unpredictability of MS.

A relapse is defined by the appearance of new symptoms, or the return of old symptoms, for a period of 24 hours or more (Burgess, 2002). There is currently no understanding of why relapses of MS occur although there are certain triggers that may contribute to a relapse (MS Society, UK, 2012). Relapses usually take a few days to develop and can last for days, weeks or months. Relapses also vary from mild to severe in intensity and remissions occur when the inflammation in the nerve tissues subsides (Jelinek, 2005, 2010).

Secondary progressive MS (SPMS)

Most people start out with RRMS and may later develop a form that is known as secondary progressive MS. In SPMS, symptoms do not go away completely after a relapse and there is a steady increase in disability (Halper & Holland, 1997; Burgess, 2002). To determine if a person has moved on to secondary progressive MS they must have shown a continued deterioration for at least six months, whether they continue to

have relapses or not (Robinson, 1990; Burgess, 2002). Current statistics suggest that 65% of people with RRMS will have developed SPMS within 15 years of diagnosis.

Primary progressive MS (PPMS)

Primary progressive MS is a relatively unusual form of MS which tends to be diagnosed in older people, usually in their forties or later. From the beginning of the presentation of MS people with PPMS experience steadily worsening symptoms and an increase in disability.

Benign MS

People with RRMS who only have a small number of relapses, followed by a complete recovery, may be described as having benign MS. It is only possible to make a diagnosis of benign MS once a person has experienced little or no disability for a period of 10 to 15 years. However, a diagnosis of benign MS does not mean they will be free of problems; a relapse may occasionally occur after many years in which the MS has been inactive (Robinson, 1990; Jelinek, 2005; MS Society, UK, 2012).

To conclude, MS symptoms range from mild to severe, and at times range from being short lived to continual. Hidden symptoms may be more difficult for those unfamiliar with MS to understand as the person with MS may appear 'normal' when in fact they are struggling with their physical bodies. People can have different symptoms at different times and, although some are very common, there is no typical pattern that applies to everyone (Perry, 1994; Jelinek, 2010).

1.3 The foundations of the thesis: a feminist standpoint

There is a greater contextualisation of the challenges raised and discussed throughout this thesis that are rooted in the politics of gender. The phrase ‘politics of gender’ emphasises the different life experiences of men and women suggesting that social interactions with powerful bodies, such as the State and Medicine, are organised to subordinate women (Mackinnon, 1994; Greer, 1999). The arguments contained within this thesis accept, to a certain extent that historically the life conditions of men have been prioritised at the cost of women’s life choices and progression, both in the private and public spheres (Walby, 1999). This quote below from Berrey (2003:13) summarises this standpoint:

I began with the premise that a consequence of living in an androcentric society is that women are oppressed. One of the results of this oppression is that women’s lives are obscured, trivialised and seen as marginal to history.

The concept of gender discussed throughout the thesis focuses specifically on the social construction of the female body. This concept of gender is then examined within the development of medical discourse. The social construction of medical knowledge was developed in the 1970s as part of the critical debates around the sociology of health and illness (Turner, 1987). There were key challenges made to the approach of biomedicine. Specific challenges were made around the assumptions that were fundamental to medical practice in general (Nettleton, 2006). Many of these assumptions were located in the biomedical model. The biomedical model is based on the assumption that disease is created by definite aetiological agents that lead to changes in the body’s structure and function (Bowling, 1997). The medical view of the body is based on the Cartesian philosophy of the body as a machine, whereas early challenges to the medical view such as Illich, (1976) and Navarro (1986) have

confronted the medical model's limited features (Bowling, 1997). For example, social constructionism argues that the medical model focuses too narrowly on the body as a machine and the use of medical technology, rather than the social context in which people live their lives (see Turner, 1987; Rose, 2006). Social constructionism also recognises the cultural and political attachments that are engrained in medical discourse (Featherstone et al. 1991) and the role these play in determining the limitations of medicine for people (Turner, 1996; Bowling, 1997). Recent studies, such as Fallon (2002), continue to challenge medical systems for their limited approach to offering medical and social care services to population groups.

Specifically, the limitations of medicine and MS are explored in this study. Chapter 2 details the key medical and social care understandings of MS and the key strands of MS research are emphasised. This provides the reader with information about the historical and contemporary understandings of MS in a medical and social care perspective. Chapter 3 further develops the theme of medical knowledge by referring to the social construction of medicine and gender. Chapter 4 specifically details the format of the semi-structured interview which investigated the women's past medical experiences in relation to experiencing MS (See pages 97-99).

1.4 Lived experience and time

Exploring the lived experiences of MS for women in this study refers to the 'physical, political and historical context of that experience' (Ellis et al., 1992). Specifically, the temporal experiences of MS will be addressed through the format of the semi-structured interview. The concept of 'lived experience' is closely linked to reflexivity, which is also discussed in Chapter 4, specifically detailing a model (and discussion)

of practically applying reflexivity to research practice. Exploring lived experience has particularly been used within phenomenology as a methodology, although not exclusively, and has been a central theme of feminist scholars in recognising the value in researching women's experiences of life. The quote below from Van Manen (1990: 36) describes an understanding of lived experience:

Lived experience is the breathing of meaning. In the flow of life, consciousness breathes meaning in a to and fro movement...a lived experience has a certain essence, a "quality" that we recognise in retrospect

In relation to this study, an exploration of the lived experiences of MS would further a discussion about qualitative research in the study of MS. (this is discussed further in chapter 11). In Chapter 4 the relationship between narratives and lived experience is further explored and detailed.

1.5 Recognising women in society

Feminist politics first gained recognition in Britain in 1903 with the Women's Social and Political Union (WSPU) which was founded by the Pankhursts (Humm, 1992).

This positioned white, middle class women from privileged backgrounds at the centre of women's campaigns and movements (Walby, 1999). First wave feminism has been accredited to securing the vote for women in 1911 (Rowbotham, 1972) and feminists believed that if women were equipped with full welfare, economic and political rights, transformation of societies could be achieved (Scott, 1988; Walby, 1999). The key aims of first wave feminism were to address the sexual division of labour, to address the inequalities of gender roles and also to support women's radical possibilities.

Liberal feminists of this time campaigned for equality believing that if women were given the right to vote they could make contributions to the public sphere and then

gain equality with men. The liberal feminist's arguments of the 1930s recognised that women should play an equal part in decision making in the State and cooperate with full citizenship. The liberal movement believed that women should be able to contribute their intellectual thoughts to societal development (Walby, 1990; Spender, 1998). One of the key drives of the liberalist movement was achieved with women's ability to vote in 1919 (although full parity was not received until 1929).

The backlash of the radical movement in the 1960s and 1970s highlighted the oppression and subordination of women recognising sexuality as the cause. Radical feminists said that there were several points that needed to be addressed for women to become full citizens (Greer, 1972; Spender, 1995). Key features of second wave feminism were for women to gain control over their sexuality; health and reproduction and an overall recognition that women could participate as themselves in public life (Greer 1972). Firestone (1970) debated that women could only be freed from their gender when reproduction could take place outside of the womb and babies could be grown in incubators. This would free women from the constraints which are placed on them when they become pregnant, such as through the job market. Dworkin (1974) stated that all men were 'potential rapists' and viewed the act of penetrative sex as being within the remit of sexual degradation for women. Furthermore, Mackinnon stated that the practise of penetrative sex should be addressed by women in heterosexual relationships as a political act for the freedom of women. In essence there was a shift in the way women were perceived as equal citizens and how the concept of equality was defined, and how this fell largely into the private sphere of women's lives. Second wave feminism attempted to explore and highlight the depths to which women were excluded. Second wave feminism also centralised, to a certain

extent, women's bodies as a site of inequality. Further discussion of this occurs in Chapter 3.

Healthcare and the experience of women

The radical approach of second wave feminism indicated that there was a need for a wider political discussion for women and their bodies in society. This structural positioning of women highlights the limitations that women experience in the social world (Nettleton, 1995). The disqualification of women's experiential knowledge is demonstrated within health practices and can be identified through the scientific rational framework within which medicine is situated (Martin, 1991). For example, the predominant discourse of scientific rationality suborns and shapes women's discussions about their bodies. When this is examined further by analysing the cultural and social representations that are ingrained in the process of applying medical knowledge, the repercussions for women in health regimes can be detrimental to their whole well-being (Grosz, 1994).

This examination of women and MS links in to, and further examines, the danger that is placed on women through the scientific rationale of the medical model. Chapter 3 further develops this viewpoint through a discussion around women, bodies and medical practices. One key argument contained within this thesis is that medicine shapes and controls women's bodies through cultural and social attachments. This suggests that the experience of healthcare for women's bodies (specifically women with MS in this study) has been influenced by the gender regimes imposed by medical authority. Furthermore the central argument of the thesis raises questions within and

around women and medicine specifically using MS to understand the experience of women's bodies in a medical regime.

The standpoint presented in this thesis recognises the difficulty in studying 'women' as a group although Chapter 4 deals with the practical aspects of reaching out to women with MS. The category 'woman' has created a great deal of discussion within feminism because the understanding of 'woman' has been defined by women, for women to have a voice. However, there are more differences between women as a group than there are between men and women (Walby, 1998; Nettleton, 2006). The arguments contained within this thesis recognise this extremely important issue of difference. The women participants in this empirical study reflected difference through the following:

- Age – the women ranged in age from 21 to 71. Observations are made in section 2 about the different experiences of women and MS dependent on age;
- Personal status - whether the women had family support, supportive relationships and how any support impacted on their lives is presented. Also, the women's ability to assert 'her knowledge and implement her rights' is explored in the empirical study;
- Access – is explored in section 2, specifically in relation to health and social care supports.

Two key arguments emerge within this thesis. One argument is that women's lives have conditions placed onto them through the experience of being a woman. A critical approach to health care is the other position that will frame the thesis argument. The term 'medical gaze' or 'medicalisation' is used to explain the view from which

medical knowledge is formed (this term was conceptualised by Foucault in 1972 and is discussed further in Chapter 3).

The standpoint of the thesis connects with debates that challenge the knowledge production and social implications for women's health (Wolf, 2001; Nettleton, 2006). For example MS is a disease of the CNS that predominantly affects women with a ratio of 4:1 (Jelinek, 2005; MS Society, UK, 2012). There are a range of theories to the origins of MS but no definite and conclusive evidence for the cause and cure of the disease (Ibid, 2005; Kalb, 2005) just key leading clinical models. Currently the bulk of knowledge around MS is within the context of the biomedical model. Chapter 2 provides a look at the historical emergence and understanding of MS, as this is key to gaining insight into the current understanding of MS. This is to enable the reader to understand the emerging narrative around MS and from which medicine currently operates in relation to MS. As Nettleton (2006:18) points out:

The body is isolated from the person, the social and material causes of disease are neglected, and the subjective interpretations and meanings of health and illness are deemed irrelevant.

1.6 The research question and key research areas

The research question is 'What are the personal and health care experiences of women with MS? The question relates to an attempt to understand the avenues of health and social care available to the women experiencing MS symptoms. These are examined through exploring and analysing the women's stories of their MS experience told through their own recollections and within the format of a semi-structured interview. This piece of research explores women's experiences with MS and looks towards the women's own health understandings to discuss and contextualise current medical processes for their experience of chronic illness. The foundation of the thesis accepts

that women have been oppressed in their experiences throughout history. The argument of this thesis suggests that women's bodies are shaped and controlled within medicine due to the limits transferred within the cultural and social stereotypes borne out of the development of medical discourse;

1. The research question supports the exploration of women's experiences with MS. The thesis argues that medicine shapes and controls women's bodies through cultural and social attachments developed within medical discourse. How has this impacted on women living with MS?

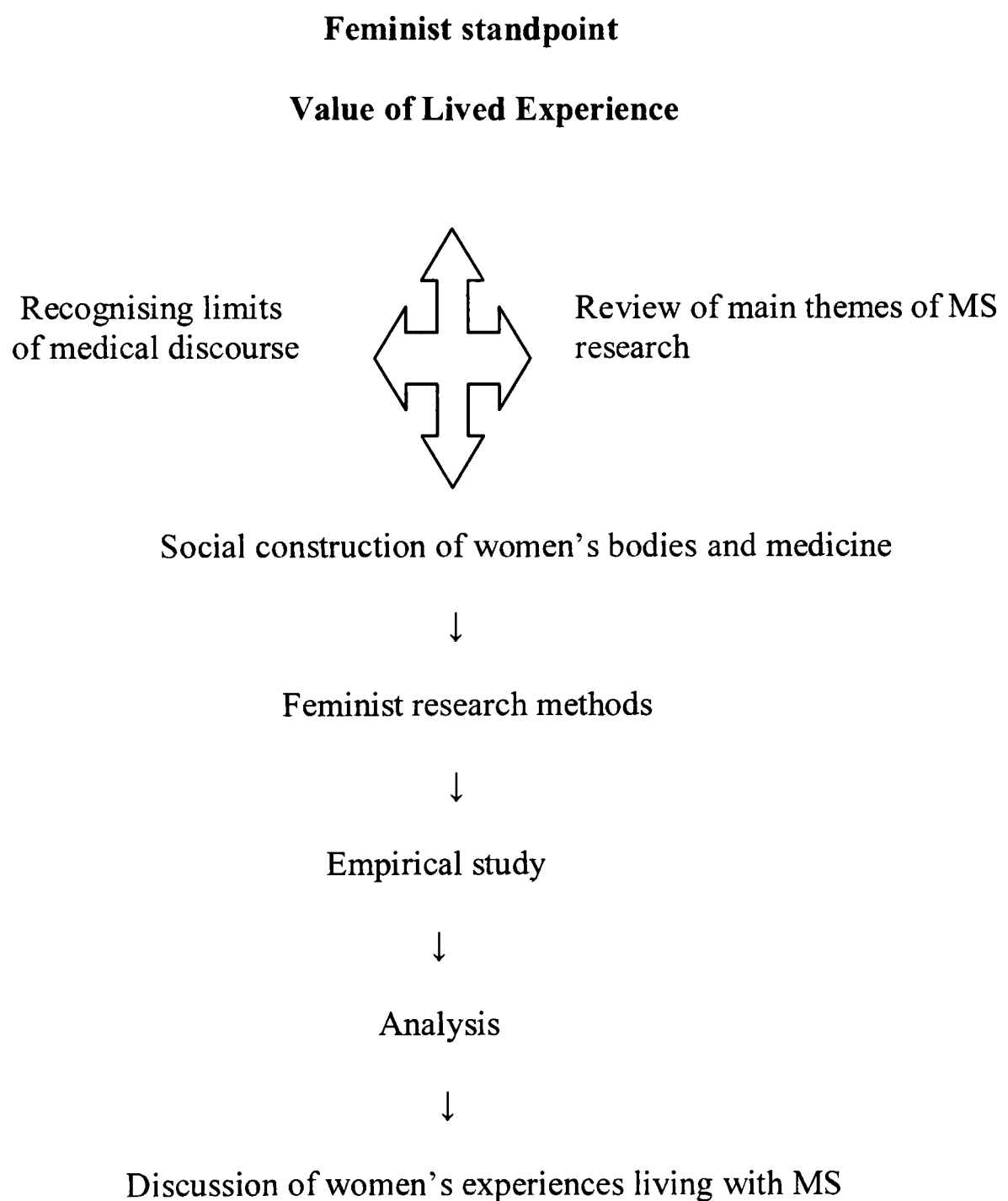
The aims and objectives of the thesis arising from the initial question included the following:

- To explore and contextualise the women's past and present experiences of healthcare in relation to MS;
- To explore the women's experiences of a diagnosis of MS;
- To explore the meaning and experience of the everyday lives of the women with MS;
- To offer a contribution to understanding the experiences of women with MS and most importantly a unique insight into their encounters with the healthcare services and personnel in the UK, and especially how these are experienced over time;
- A contribution to a wider understanding of women, health, experiences and the lived understanding of gender particularly in relation to the relationship with the medical profession who have the overall position in law and society to make diagnoses which can have a significant impact on people's lives; An

assessment and review conducted of interdisciplinary literature that has informed the research question and overall study.

Diagram 1A illustrates the focus of the research question

Research question: What are the personal and health care experiences of women with MS?



1.7 Logic of thesis structure

The thesis has been organised in 2 sections. Section 1 is the backdrop to the empirical study and section 2 is the empirical study, analysis and the conclusion of the study.

The focus of the thesis aims to explore the women's relationship with their own bodies and the experience of MS. Analytically this thesis identifies any tensions that the women may feel due their experiences within medicine. As Frank emphasises (1995: 135-6):

Medicine does...occupy a paramount place among those institutional practices by which the body is conceptualized, represented and responded to. At present our capacity to experience the body directly, or theorize it indirectly, is inextricably medicalized.

Foucault (1980) recognises the reality of power production which is also similar to Mills' (1971) socially constructed 'cultural apparatus'. Foucault (1980: 194) suggested that:

We must cease once and for all to describe the effects of power in negative terms: it 'excludes', it 'represses' it 'censors', it 'abstracts', it 'conceals'. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth. The individual and knowledge that may be gained from him belong to this production.

The purpose of critical social research is to connect and bring together the personal, social and structural relations, and in this instance, the experience of MS for the women in the study. This will be achieved by starting from the position of their experiences. Women's bodies historically have been identified within particular discourses that normalise and reproduce a particular narrative that negotiates identity (Oakley, 1980; Martin, 1989; Goudsmit, 1994) and normalises self regulating behaviour. Reflexivity is a central facet of this thesis and travels alongside the temporal journey of the research process nurturing and developing the narrative trajectory.

This chapter has presented the key ontological, theoretical and practical components of the thesis and the key arguments to be contained within it. Here is the layout of the thesis structure and a brief overview of what each chapter will contribute to exploring the lived experience of MS for women:

Chapter 2 reflects some key literature themes around medical and social care perspectives about MS. This chapter, in part, addresses the early and contemporary understanding of MS from mainly medical leads of key research areas around MS. This is because to date, the large majority of research about MS has been conducted in a medical setting. This chapter further recognises the impact of medical research on MS such as medical treatments. There is also a review of some social care and social science studies and perspectives although the themes of these are limited.

Chapter 3 identifies the female body as being a site for exploring and understanding experiences in medicine. Firstly, this chapter looks at some key debates concerning the study of women and the body. Secondly, this chapter recognises research conducted around women's bodies and medicine, noting some key theoretical perspectives. Specifically, this chapter highlights the processes of medical authority that are interwoven with the social and cultural imprints of the construction of the female body.

Chapter 4 firstly offers a brief overview that highlights some key concerns in relation to health research. This challenge to healthcare is interplayed throughout the thesis therefore a brief overview is enough to situate the methodological assumptions of the thesis. Then this chapter outlines the methods and the construction of the empirical study. A feminist model of reflexivity is displayed and discussed. Furthermore, the chapter discusses the use of a narrative study; the conceptual frameworks of the

analysis; the feminist underpinnings of the methodology and concludes by reflecting on the pilot study.

Section 2

Chapter 5 presents the women's narratives around the time they first experienced symptoms of MS. The women tell distressing stories about their first 'attacks' of MS and recall many dismissive interactions with doctors and other medical professionals. This chapter raises questions over the role of medicine and the identification of MS symptoms and also explores the medical responses provided to the women. This chapter concludes with an illustrative study highlighting the impact of experiencing MS symptoms and having no medical understanding for them.

Chapter 6 outlines the women's experiences of obtaining a diagnosis of MS. This chapter explores the concepts of time and emotion to understand the women's experiences of a diagnosis of MS and offers insight into the medical practices as self reported by the women. For example, they often reported that neurologists provided them with little or conflicting information. Equally, the women reported positive aspects, such as becoming more proactive in their own lives around obtaining information. There is also a discussion around age and experiences, particularly relevant due to the long time scales from first symptoms to diagnosis.

Chapter 7 looks at the health services and supports the women outlined in their interviews. This chapter identifies and charts some key issues raised by the women in relation to service provision and MS which were both positive and negative. This chapter will further this discussion by linking the current care practices on offer to women living with MS and look at how the women engaged with these practices.

Chapter 8 explores the women's own interpretations of the start of their ill health. This chapter links the theme of trauma to the onset of the women's MS symptoms.

The sub-themes related to trauma are explored highlighting some key stories to explain the women's own understanding of illness.

Chapter 9 explores the women's personal relationships and living with the progression of MS. The women's narratives are presented in this chapter highlighting how they coped with their MS and what emotional and practical supports they had. There is a specific section which highlights the women's narratives that had few support networks (in terms of family and friends) and also employment issues are outlined.

Chapter 10 explores the women's discussions of adapting to their changing physical bodies whilst living with the uncertain and random symptoms of MS. Many of the women offered uplifting and power outlines of how hope, or the concept of hope, is woven into their life trajectories.

Chapter 11 is the conclusion of the study. This chapter brings together the whole thesis emphasising the original contribution to knowledge which has been offered within this thesis. The conclusion will address the research question and the proposed aims and objectives to assess what has happened in the whole research process. Key suggestions will be made about the future for women and MS and will relate to the findings developed through the carrying out of this study.

Chapter 2:

What are the key perspectives on MS generated by medicine and social care?

Prologue

This chapter provides the reader with an understanding of MS from a historical and contemporary perspective (which until 1960 is medical). Furthermore, a review of social care and social science contributions to MS are outlined and discussed (specifically from 1980 onwards). This chapter, in part, addresses the early and contemporary understandings of MS and maps out the framework from which current day understandings of MS derive.

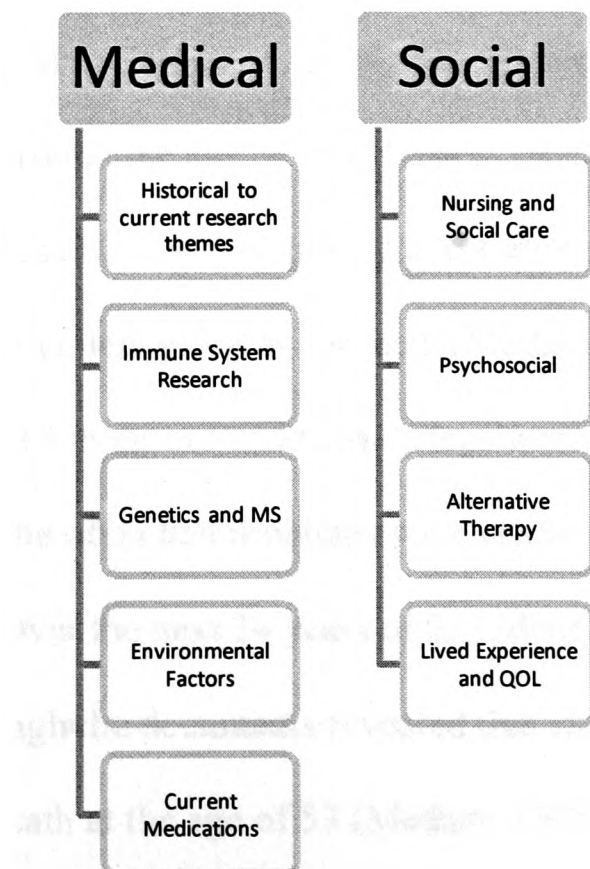
This chapter provides a backdrop to the design of the research and also to understand the empirical findings. In section 2 of the thesis the empirical findings are discussed with specific detail provided about the diagnosis and the treatment of MS. A key argument advanced in this thesis shows how medicine has shaped and controlled women's bodies through cultural and social attachments and therefore information about the formation of MS as a medical and social care narrative has been provided.

Introduction

This chapter contains a review of and discusses the medical and social care understandings of MS (Appendix 1 contains details of the literature review process which occurred to obtain the content of this chapter). Key perspectives on MS with a focus on the following themes (detailed further in diagram 2A):

- A brief history of when and how MS became a medical condition;
- An overview of key medical perspectives of MS. Also current medical treatments for people with MS;
- An overview of social care and social science contributions to the study of MS;
- A discussion of the literature review provided in all of the above, further developing some of the above themes.

Figure 2A details the themes of this chapter of medical and social literature



2.1 The medical identification of MS

Early cases of MS

The earliest documented case of MS has been identified in the 14th century (Compston 2004; Jelinek, 2005). This was discovered in the historical documents of St Lidwina of Schiedam (Medaer, 1978; Compston, 2004; Jelinek, 2005). St Lidwina was a Dutch Saint who lived in Holland and lived from 18th April 1380 until 14th April 1433. She was the daughter of a wealthy nobleman who then lost his fortune and St Lidwina was raised in extreme poverty. She was canonized on the 14th March 1890 by Leo XIII and it is well documented that she regularly carried out fasts for spiritual practice. St Lidwina's patronage was against sickness and she is the recognised patron of ice skating - she is often represented in imagery on ice skates (taken from <https://saints.sqpn.com/saint-lydwina-of-schiedam/> accessed on 09/09/2012). The unearthed historical texts have revealed that she was afflicted with a debilitating disease. The description of the debilitating disease was characteristic with what would be currently recognised as MS (Compston, 2004). Her illness, or MS, started after she had fallen whilst skating around the age of 16 (Medaer, 1978). It was noted that after the fall the symptoms of illness, or MS, appeared and further developed into walking difficulties, headaches and violent pains in her teeth (Medaer, 1978; Compson, 1992). By the time she was aged 19, both of St Lidwina's legs were paralysed and her vision was greatly affected and she often had problems with visual disturbances (Medaer, 1978; Compston, 2004). Over the next 34 years of St Lidwina's life her overall health slowly deteriorated, although the documents revealed that she had periods of relapse and remission, until her death at the age of 53 (Medaer, 1978; Halper & Holland, 1997; Jelinek, 2005). St Lidwina's symptoms were consistent with those of MS (by today's diagnosis procedures), as were the age of onset, duration and course of

disease (Compston, 2004). St Lidwina had recognised periods without MS symptoms which signify she probably had Relapsing Remitting MS (RRMS). Together these factors suggest that a posthumous diagnosis of MS may be conceivable for Lidwina's condition and thus locating a case of MS back to the 14th century (Compston, 2004).

The next recognised description of MS did not appear until the 19th century when a first hand account of MS was provided through the personal diaries of Sir Augustus d'Esté who was the illegitimate grandson of George III of England (Fredrikson & Kam-Hansen, 1989). The details of D'Esté's MS were recorded in a diary over a 26 year period (Ibid, 1989; Jelinek, 2005). Like Lidwina's onset of illness, D'Este's ill health preceded a minor health problem. D'Este had noted that his first symptoms began after he had been ill with the measles (Ibid, 1989). Similar to other cases of MS his symptoms affected his body so that he became debilitated. Also an attack of symptoms at this time started the disease on a chronic progressive course with only partial recovery after each relapse (Ibid, 1989). This probably signifies that D'Este's MS was progressing from RRMS to Primary Progressive MS (PPMS). D'Este died in 1848 whilst both his arms were paralysed (Ibid, 1948; Ibid, 1989). Like St Lidwina, D'Este's physician was unable to diagnose MS as it was not a recognised condition at this time. It was to be another 20 years after his death before MS became a recognised condition or disease (Ibid, 1948; Ibid, 1989). Retrospectively D'Este, like St Lidwina (Compston, 2004) has been posthumously diagnosed with MS (Ibid, 1989).

MS and developing medical perspectives

An MS clinician in the first half of the 18th century was Jean Cruveilhier (1842) who described the pathology of the lesions seen in MS (Ibid, 1989). Cruveilhier's (1842)

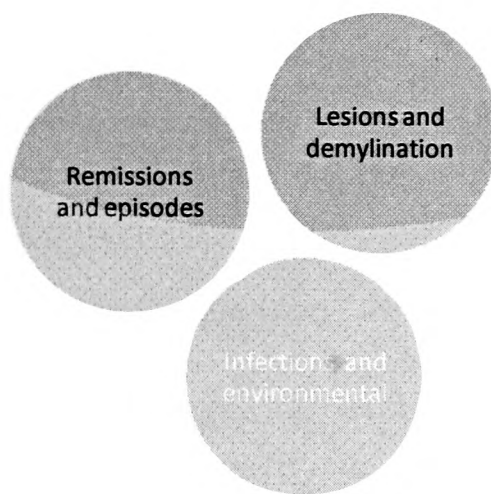
contribution to the current day understanding of MS was to record the clinical history of a patient later found to have neuronal lesions (Ibid 1989). Cruveilhier's (1842) notes from that time describe that the woman *'had been ill six years without cause ... she noticed that the left leg resisted her will to such a degree that she fell in the street'* (Cruveilhier, 1842). His notes described how over several years, the patient developed severe symptoms, that resulted in decreased mobility. These presented as weakness of both legs and arms, spasms, difficulty in swallowing and visual disturbances and from this he diagnosed further *'a lesion of the upper portion of the spinal cord'* (Cruveilhier, 1842). In today's understandings of MS the recognition of lesions would be a central theory related to the debilitation which occurs in people with MS (Burgess, 2002).

In 1849 the German pathologist Friedrich Theodor von Frerichs contributed to medical understandings of MS through recognising the occurrences of remissions in MS. Frerich's (1849) clinical account recognised remissions as a characteristic feature of MS and this was the first time the recognition of remissions had been given (Ibid 1989; Halper & Holland 1997; Jelinek, 2010). Frerich's (1849) also offered the first medical description of mental disorders in MS recognising the impact of symptoms on cognition.

In 1865 Dr Jean Charcot (1825-1893) was the first scientist to describe, document and identify MS in 1868 (Halper & Holland, 1997). Charcot developed a research school (Salpetriere) which was the first scientific place to dedicate time to researching the causes and understandings surrounding MS. During his research career Charcot was convinced that MS was a defect in the glial tissue and he was certain that MS was

caused by environmental toxins (Halper & Holland, 1997; Compston, 2004). From this period it was believed that MS was considered an episodic disorder. (Compston, 2004). In 1894 Pierre Marie (a former student of Charcot) suggested that MS was an infection although Marie could not identify the specific infection that related to MS. Pierre Marie was convinced a cure would appear in the form of a 'vaccine of Pasteur or lymph of Koch' (Murray, 2004).

In 1938 Dr V.B. Dolgopol described a case of optic neuritis which he believed was caused by severe demyelination. This area would later become a central theme of MS research. From 1960 and onwards vascular theory for MS became an interest for clinical researchers because of the development of anticoagulants (Murray 2004). Then an interest in dietary factors emerged with a connection to vascular defects (Murray 2004). From early 1800 to 1960 there were key perspectives emerging about the development of MS in human beings. (These perspectives would be further developed, and continue to be today).



Early information about MS

Figure 2B presents the information identified about MS from 1800 to 1960

2.2 Key medical research themes

Current medical opinion suggests that once disability has occurred through MS, although symptoms may improve, normal function cannot currently be returned (Murray, 2002; Burgess, 2005; Jelinek, 2010). Furthermore, Reynolds et al. (2011) and Patti (2010) both assert in recent research articles into the current diagnostic criteria for MS that it is still an incurable, degenerative disease. Jelinek (2005: 21) reinforces this when he states:

Once disabled, although there are many therapies and aids that will make life easier (for people with MS) at present, the conventional medical teaching is that normal function cannot be restored.

The point highlighted by Jelinek (2005) is also highlighted by Kalb (2005:10):

At the present time, we have very little control over the neurologic changes (impairments) that occur in MS; we do however, have effective treatments that have been shown to impact the disease course.

The suggestion that MS is still a puzzling condition within medicine remains today (although key advancements have been made which will be highlighted in this chapter). Murray (2002) asserts that it is difficult to think of a theory that has not been suggested in relation to MS and claims that many of the questions that have been asked over the past 150 years still remained unanswered (Murray 2002). This claim by Murray (2002) is reiterated also by Noseworthy and Hartung (2006) who suggest that scientists are still puzzled by the same questions about MS.

Reingold (2002) suggests that current medical theories about MS have developed around 4 themes. These 4 themes cited by Reingold (2002) and other clinicians working in the area of MS are:

1. That MS is classified as an autoimmune disorder (Ibid 2002; Burgess 2005). This is when the immune system attacks a normal tissue or organ in the body (Kalb, 2005);
2. That there is a genetic susceptibility in people who develop MS (Murray, 2002); Although this is not conclusive, medical evidence suggests that there can be a genetic susceptibility. Smith and Schapiro (2005) suggest that some people are more genetically predisposed to develop MS;
3. There is probably an infectious trigger that starts off the MS (if not a cause) (Murray, 2002). Murray (2002) asserts in his research paper that infection could be a cause of MS;
4. Inflammation is the cause of the signs and symptoms of MS (Ibid 2002; Burgess 2005; Jelinek 2005; 2010; Ascherio, 2010).

Please note that these 4 research concerns about MS have been prevalent since the emergence of MS as outlined in 2.1. These research concerns will now be discussed in more detail.

Immune system and MS

Since early 1990 the relationship between MS and the immune system has been a key focus of investigation (Reingold, 2002; Compston, 2004). The results of clinical studies carried out in early 1990 revealed that people with MS have reactive immune cells in the blood and the CNS against a protein component of normal myelin (see Goodkin et al. 1996; Holland & Halper, 1997; Murray, 2002; Herrera, 2006). Further studies confirmed that a variant of T Cell enters the CNS and orchestrates or mediates an immune response against myelin (Goverman, 2011). Recent studies by Yong et al. (2009) and Kasper et al. (2010) reinforce the activity of the immune system in MS and other autoimmune conditions such as Alzheimer's disease. Kasper et al. (2010) note that to date therapies based around the immune system for people with MS are not always consistently therapeutic and quality of life enhancing. Further study in this area, which specifically focus on the role of the T Cell as a mediator for MS, continues to develop with the aim of developing more specific therapies that could help control and suppress the progression of MS (Murray, 2002; Reingold, 2002; Herrera et al. 2006; Rack et al. 2010).

Genetics and MS

Medical research on genetics and MS has derived from evidence on family studies which suggests that 20% of people with MS will have another family member with the same condition (Noseworthy et al. 2006). The risk for this is currently relatively

low, and although research studies from Canada indicate that family links were genetic and not environmental, the current risk for developing MS when it has already presented in the family is 1/1000 per family (Noseworthy et al. 2006). In 1996 3 major international studies concluded that their data on genetics and MS was proving inconsistent, but that MS was a complex, multi-genic disease with areas of genetic 'interest' (these focused on several chromosomes see Haines et al. 1996 for details). A recent study on MS and genetics in 2007 identified 2 genes associated specifically with people with MS and the findings suggested that there was a hereditary link to MS (but this did not indicate that all people with these 2 genes would go on to develop MS) (Jones, 2002). Currently the genetic factor in MS is treated as relevant but not a defining factor for developing MS. For example, some medical researchers would recognise MS as being an autoimmune disease that is influenced by both genetic and environmental factors as to whether the disease will develop (see Rubtsov et al. 2010 for further scientific discussion of triggers for autoimmune diseases).

Environmental factors and MS

The most likely environmental factor for MS is an infectious trigger (Johnson et al. 1998). A recent study by Ponsonby et al. (2004) suggested that having an increased number of younger siblings proved to show a significantly reduced risk of developing MS. This is because younger siblings often experience common viral infections and having this close contact has a positive effect upon the immune system. Another study by Willer et al. (2005) made a link between month of birth and the development of MS in the Northern Hemisphere. Willer et al. (2005) stated that there is a greater risk of MS in countries furthest from the equator. Willer et al. (2005) suggest that the effects of UV radiation on the mother during pregnancy could affect the development of the immune system and nervous system. A study by Banwell et al. (2007) into

childhood cases of MS concluded that there was a link between Epstein Barr Virus (EBV) and the presentation of MS in children. It was concluded that MS might be associated with exposure to EBV, suggesting a possible role for EBV in MS pathobiology. There have been multiple studies into a possible link between EBV and MS and a recent study by Haar and Hollsberg (2011) concluded that the development of an EBV vaccination would test the hypothesis of EBV and MS link, and they predict a vaccination could eradicate both diseases. Jelinek (2010) outlines that research to date suggests that the virus known to cause glandular fever, (the EBV) is implicated in the development of MS. Jelinek (2010) determines that a susceptibility to climate and environmental factors, together with EBV infection, could in combination trigger illness in later life. However, Jelinek (2010) stresses that although a link may be proved in the future it doesn't mean that a cure will be found. A study by Noonan et al. (2010) based on the prevalence of MS in 3 communities in the USA concluded that there is a link between a lack of U.V. sunlight and the latitude locations of the communities studied and the prevalence of MS. Further research into the role of vitamin D deficiency and MS is also highlighted here as relevant.

Inflammation and symptoms of MS

Key research questions in MS research have focused on demyelination as a main process in MS and the cause of symptoms (Rudick et al. 2007). Demyelination refers to the myelin sheath which covers the nerves, and when this is damaged by inflammation, a part of the myelin sheath can be temporarily or permanently damaged and this process usually results in MS symptoms (Rudick et al. 2007; Jelinek, 2010). The symptoms that are presented depend on which part of the myelin sheath is inflamed. Khan et al. (2010) suggest that until recently MS has always been defined as a chronic inflammatory disease of the nervous system and this was mainly linked to

the process of demyelination rather than neurodegeneration. Khan et al. (2010) purports that neurodegeneration can in fact occur separately to demyelination thus raising challenges to the role of inflammation in disease activity within MS. (Demyelination is the process under investigation through the MRI scan for diagnosis – Chapter 6, 6.1, details this further).

2.3 Current key medications for MS

Currently there are a range of conventional medical therapies that are part of, and continue to be the medical research trajectory for MS. These are set out below:

Corticosteroids commonly referred to as steroids (please see appendix 1 for BNF description)

The majority of neurologists prescribe steroids (please see appendix 1 for BNF description) for acute relapses for people with RRMS. Steroids (please see appendix 1 for BNF description) are a proven effective treatment for people with MS (Wandinger et al. 1998; Zajicek et al. 2010) with MRI scans showing a reduced swelling around the inflamed lesion within hours of taking the first dose (Jelinek, 2005; Zajicek et al. 2010). A study by Beck et al. (1993) highlighted that intravenous steroids (please see appendix 1 for BNF description) were more effective than those taken orally. They examined the treatment of people with optic neuritis (an inflammatory nerve condition of the eyes which always develops into MS) with intravenous and oral steroids (please see appendix 1 for BNF description) and found that by taking intravenous ones there was a delay in the development of MS. In Randomised Controlled Trials (RCT's) and the use of steroids (please see appendix 1 for BNF description) and MS results show that steroids (please see appendix 1 for BNF description) are useful in improving recovery after a relapse of MS (Johnson et al.

2010). There is also research that shows steroids (please see appendix 1 for BNF description) may be beneficial to all types of MS and slow down the rate of disability (see Fog, T, 1965; Goodkin et al. 1998). However, steroids (please see appendix 1 for BNF description) have only shown to be effective when used in the short-term and there is no support for using steroids as a long-term medication.

Interferons (Please see appendix 1 for BNF description)

The interferon treatments are taken via an injection in the muscle 3 times a week. To date, only one RCT study has shown a delay in disease progression, although the benefit for using is relatively small (Jelinek, 2010). However, the reported side effects for taking interferon are high, with most people experiencing flu like symptoms on a weekly basis (Dubois et al. 2003). In fact Dubois et al. (2003) report that the quality of life for people taking interferon is not improved largely due to the side effects reported. Jelinek (2005) notes that during the RCT trials for interferon there was a high dropout rate due to the difficult side effects, which is a major concern for people's long-term quality of life especially when results show improvement as being small.

Glatiramer Acetate (or also known as Copaxone; please see appendix 1 for BNF description)

Glatiramer Acetate works by re-educating the immune system and stopping the activation of certain triggers which cause the damage to the myelin sheath (Jelinek, 2005). Early studies on Glatiramer Acetate showed that it was effective in the slowing down of relapses in RRMS and did not impact negatively on the quality of life due to very low side effects (Bornstein et al. 1991). A recent study by Racke et al. (2010) promotes the therapeutic benefits of this drug suggesting that initial positive outcomes for taking Glatiramer Acetate are now even more encouraging than first thought.

Other medications

There are a range of medications that are regularly prescribed for people with MS and these are related to symptom management. Due to the wide, varying nature of MS symptoms each person with MS may be offered a range of medications to assist their symptoms. These include anti-depressants and anti-inflammatory medications.

2.4 Social care and social science research contributions to MS

Section 2.4 identifies research that has attempted to encapsulate the social impact of MS, the psychosocial effects of MS, the decline of physical ability and the experience of MS. Since 1980 there has been a significant increase to social science literature related to MS. The emergence of social care and social science research literature raised fundamental questions about MS specifically commenting around the social and cultural processes attached to medical literature. Examples such as examining the relationship between physician and patient (Stewart & Sullivan, 1982) or an examination of the relationship between culture and chronic illness (Duval, 1984) reflect this. The themes of Nursing and Social Care and MS; Psychosocial Adaptation to MS; Alternative Therapy and Lived Experience, MS and Women will follow below.

Nursing and Social Care and MS

From 1980 onwards literature emerged identifying the difficulties for nursing and social care supports in supporting people with MS. These difficulties were mainly related to the variations and inconsistency of symptoms presented by people with MS.

A first study in this area by Catanzaro (1980) studied the nursing care of the MS patient suggesting that MS was a particularly challenging disease to deal with.

Catanzaro (1980) observed the range of health needs associated with MS including

the maintenance of physical, psychosocial, social health, evaluation and management of symptoms and appropriate referrals. The conclusions from this study suggested an approach to care which centred on key social and psychological problems in the daily experience of people living with MS.

Halper and Holland (1997) provided a text book approach to overall nursing care needs for people with MS whilst developing a 'wellness model for care' which incorporates the concept of hope in nursing practice. Halper et al. updated their book in 2010 which reflects on changes in MS over the previous decade. They specifically raise challenges faced by nurses in the era of information on the World Wide Web. Furthermore, a study by Burgess (2002) based on her research and practice as an MS nurse at Hope hospital in Manchester raises similar issues as Catanzaro does in 1980. Burgess recognises that a neurological framework has developed over the past 20 years, yet she identifies the constraints placed on practice and service delivery. These challenges are related to quicker referral procedures, symptom management support, evaluation of clinics and emotional supports.

In 2006 Forbes et al. conducted an evaluation of a MS specialist nurse programme at 6 neurological services in 4 different locations in England. The data collection compared services that had the post of MS nurses and services that did not have the post of MS nurses. The aim of the evaluation was to identify the impact that MS specialist nurses have on the treatment and support of people who have MS. Data was collected in the form of a postal questionnaire from 753 participants (out of a potential 1510). The results of the study showed that MS specialist nurses had provided a service to support people with RRMS and this proved to enhance psychological well

being in people with RRMS. These research projects and articles highlight the impact that service delivery has on the lives and well-being of people living with MS.

In response to the number of studies which have raised questions about the role of medicine and MS, Carter, Mckenna et al. (1998) conducted a study comparing the responses of health professionals to MS and Motor Neurone Disease (MND). The health professionals were assessed in their responses to patients of both conditions in order to compare similarities and variations by workers. The results showed that health professionals were more negative about MND than MS. This was shown in how they helped patients with many of the health professionals feeling able to offer more help to patients with MS. In relation to the management of the two conditions there was little difference, although in both conditions the health professionals found the progressive disability difficult to deal with. The results of this study show that health professionals need to find new ways for communicating within different health care settings so that peer support and learning can be gained. Also there are implications for changing health professional's conceptualisation of 'hope' and developing ways of improving communication between health professionals overall. A key finding from the study also showed that the health professionals wanted to address the significant gaps in service provision that impact on young people with MS.

Psychosocial adaptation to MS

Brooks & Matson (1982) conducted a 7 year long piece of research which analysed the adjustment process to living with MS. The findings from this research study highlighted that the majority of the people who took part in the study had made a

satisfactory adjustment to living with MS. This was measured by the use of positive self concepts identified during the longitudinal study. They also found that those who had accepted having to live with the symptoms of MS were doing better in their lives. Another study which focused on psychosocial adaptation to MS was by Walsh & Walsh (1989). Walsh et al. (1989) concluded that self esteem for people with MS was related to how well they adapted to MS symptoms (Further work by Robinson 1990).

Antonak & Livneh (1995) conceptualised the psychosocial adaptation to disability using MS as an illustration. Antonak et al. (1995) suggested that basic research questions need to be addressed to construct a theoretical model for the process of adaptation to chronic illness. A similar study, which developed the findings from Antonak et al. (1995), was by Guagenti-Tax et al. (2000) who evaluated a comprehensive model of a long-term care programme for people with MS. Both studies made key recommendations on implementing long-term care programmes within community resources. Guagenti-Tax et al. (2000) conducted their study as a RCT measuring the impact of a comprehensive program of care for people and families living with MS. This was a longitudinal study and there were a range of key findings for the role of rehabilitation and MS. Like many of the studies to date the conclusions for this research confirmed that the unpredictability of MS cannot always be catered for within traditional health intervention methods.

Aronson (1997) looked at the quality of life among persons with MS and their caregivers. As Aronson suggested there have been very few studies that have looked at the psychosocial aspects of chronic illness and this research brings awareness to the fact that illness is not just a physical decline, but also an emotional, social and psychological struggle. Aronson et al. (1997) conducted a population study with a

quality of life study to look at the issue of MS and carers. Survey methods were used and this was a large sample of 697 people with MS and 345 of carer's. The objectives of the study included determining QOL as a whole including variables of demographics and physical disability. Overall people with MS reported that health was their lowest satisfaction point in the scale of 6 components. MS was also the biggest interference in social activities. QOL was poorer for the carers who were looking after a spouse and for those carers who had been caring for a long time period. The carers QOL were also related to the severity of the symptoms experienced by the person with MS. The conclusions to this study centre on the importance of understanding the QOL for people living with MS and their carers. Aronson et al. (1997) suggested that if there were more supports to assist carers in their roles that there could be less institutionalisation of people with MS.

In 2002 Boeije et al. carried out a qualitative study of individuals in the downward phase of MS. The authors specifically looked at how people with MS accommodate their illness. The research was conducted using semi-structured interviews with both the people with MS and the family caregivers. The methods used were semi-structured interviews with biographical work and analysis so that the research team could look at the meaning given to the decline of health. The data was analysed by constantly comparing between the 2 interviews – one from the person with MS and the other the family caregiver(s). The conclusions of the study suggested that due to the severe decline in health the concept of the self for the person with MS at times presented as being lost. The authors described this as 'the loss of salient aspects of self'.

Alternative Therapy and MS

At the turn of 1990 there were several studies looking at the use of alternative therapies for people with MS (see Huntley et al. 2000; Bowling et al. 2003). Fawcett et al. (1994) did an exploratory study into the use of alternative therapies for people with MS. 16 people with MS took part in the semi-structured questionnaire and the results showed they had sought out several forms of alternative therapies because they felt the biomedical model currently offered no support for symptoms of MS. Other studies stipulated that alternative therapies were used to meet the needs of people with MS, which were otherwise not being addressed in medicine (see Nayak et al. 2003). Page et al. (2003) conducted a survey review of people with MS using Complementary and Alternative Medicines (CAM). The survey response was 447 and 70% of respondents sought CAM rather than rely on medical therapies. The 30 % not using CAM did not due to the lack of information and education around benefits.

Lived Experience, MS and Women

Jackie Barrett (1995) did one of the first pieces of research that attempted to engage with exploring the meaning of a diagnosis of MS for women. (Barrett is herself a woman with a diagnosis of MS and uses autobiographical accounts of herself and her family in this research paper). Barrett's article explored the dynamics that a diagnosis of MS creates drawing on a framework of traditional anthropology concepts relating the acceptance of MS to being a rite of passage. Barrett (1995) provides the reader with an understanding of going through the process of acceptance. A similar autobiographical paper by Helen Meekosha (2000) raised questions about the representation of women with MS within popular culture. Meekosha (2000), like Barrett (1995) laid raw the emotive tensions brought out by a diagnosis of MS.

Meekosha (2000) demonstrated in her paper that the relationship between the self and theory can be interwoven to produce a knowledge contribution to the study of health and illness.

In 1997 Miller conducted a study of people living with Relapsing Remitting MS (RRMS). Miller's (1997) study contributed a descriptive account of the lived experience for people with RRMS. Miller used a hermeneutic phenomenology conducting 10 interviews with people living with RRMS and the analysis of the data was conducted using the Colaizzi method of hermeneutic phenomenology. Miller found that the themes of lived experience for people with RRMS reflected uncertainty, fear and loss, control and a sense of hope. Miller concluded that it is crucial for neurological nurses to be aware of the RRMS experience in order to offer hope and support to people and families with this form of MS. In 1999 Koopman et al. explored the experience of living with MS symptoms prior to a diagnosis of MS. The study involved 5 in-depth interviews with selected participants exploring the diagnosis of MS. The conclusions highlighted that the provision of up to date information, sensitivity around the variety of MS symptoms and hope for the future were prevalent in the diagnosis process.

Dyck (1995; 2000) has contributed 2 key studies to the literature of women and MS. Dyck's first study in 1995 looked at how women with MS negotiated the physical, social and economic consequences of their illness. Dyck (1995) conducted in-depth interviews with 20 women that focused on the relationship between space, place, gender and health. These themes were explored analysing the everyday experiences of women living with MS noting the complex strategies used by the women to adapt and

rebuild their lives. The results of the study conclude that viewing the body in both a geographical and social context is a credible way of exploring the subjective and social context of the experience of illness. Dyck carried out another study in 2000 looking specifically at employment issues for women with MS. The study used both in-depth interviews and survey methods for data collection. The sample size for this study was over 30 participants. The results of this second study indicated that although severity of symptoms effect the employment status of women with MS there were key structural effects on the women's employment status. These related to factors such as work conditions and understanding employers, and good support at home, can enhance women's ability to work after a diagnosis of MS.

Ford et al. (2001) looked at the status and quality of life of men and women with MS through the use of action research which aimed to understand and then make a change around supporting people living with a chronic illness. The groups of people who were in the study were men and women that live with MS and men and women that live with diabetes 2. The results of the study showed that there are 'critical turning points in the illness transition experience' as well as noting that storytelling is a way of expressing the journey of chronic illness for the person experiencing it. The conclusions of this study suggest that health care professionals need to gain some understanding around how people learn to live with chronic illness. For example once the health professional can grasp how chronic illness is accepted within people's lives they can then contribute effectively to their self care management.

In 2002 Koch, Kralik & Eastwood conducted a study on women in Australia who live with MS. The aim of the study was to explore understandings of the body, sexuality

and the changing boundaries of the body for the women living with MS. The data collection was carried out through group sessions which in turn led onto two one to one in depth interviews. For this study the in-depth interviews were highlighted so as to gain an in-depth understanding and exploration of women's relationships with their bodies. Conclusions for the study discussed how the women shape and interact with their bodies as they change through illness. Kralik et al. (2003) outlined that the body is central to the women's experience of MS and the choices that are available to them. They suggest that awareness of choices is central to empowering the women into reshaping their sexual and cultural identities.

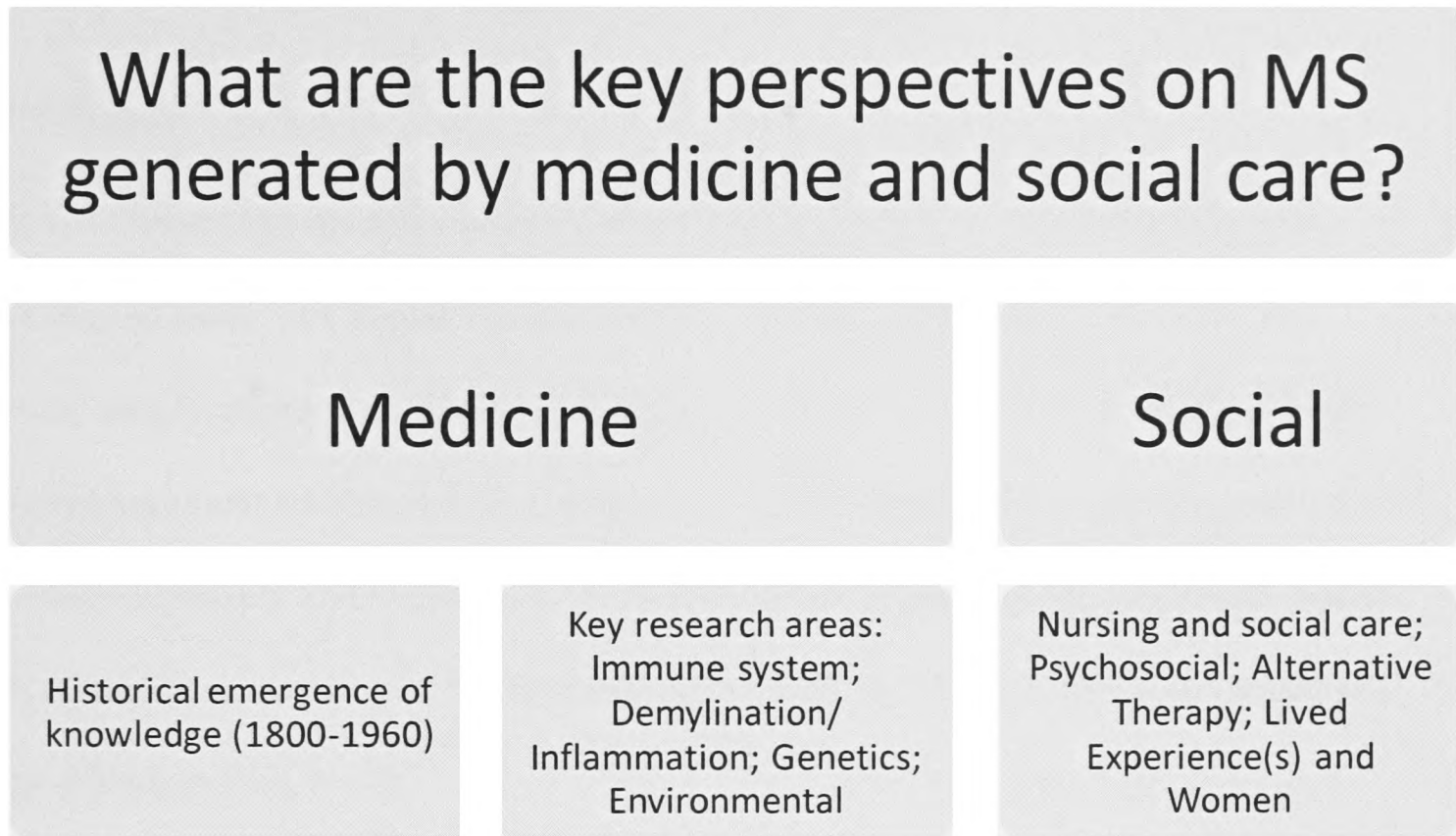
In 2008 Olsson et al. conducted a study specifically about women living with MS in Sweden. The aim of the study was to describe the meaning of women's experiences of living with MS. Olsson et al. carried out the study using a qualitative hermeneutic phenomenology interpretation. 10 women were interviewed in this study and Olsson et al. suggested that the meaning of living with MS for these women related to the body and how the women cope with their changing bodies. Olsson et al. (2008) suggested that through the women's ability to keep power over their disabling bodies is central to how they express their lived experience of MS. For example, Olsson (2008) notes that the women recognised their bodies to be hindrances in their everyday lives and the women also struggle with issues of dignity because of this.

2.5 Summary of the key perspectives on MS from medicine and social care

This section has highlighted the key research areas that have contributed to the journey of knowledge that has been produced over the last 150 years about MS. Medical research studies have inputted greatly to the shaping of the knowledge and the establishment of understanding about MS in relation to the body (as outlined in section 2.1-2.3). Section 2.1 provided the reader with the emerging medical narrative of MS. This was developed from the 18th century, and today in 2012, clinicians are just as baffled about the cause of MS. There are clear developments as outlined but as of yet, the cause and cure of MS is still the priority for medical researchers. The social care and social science context of the review covers key themes of study in the area of MS showing the range of input provided to the development and support for people living with MS. As Reingold (2002:29) suggests:

“Whilst most research is – and should be – aimed at understanding the disease process improving the quality of life for those with MS, and developing safe and effective treatments, the whole person is the subject of modern research in MS”.

Figure 2C displays the themes of Chapter 2:



Chapter 3

Taking a feminist standpoint: the social construction of women and medicine

Prologue

In this chapter the specific content situates women's experiences of the body as a subject of study. In Chapter 1 it was outlined that the standpoint for the empirical study was to examine women's experiences of MS, in part, within the medical model. A key argument advanced in this chapter has been to highlight the specific position of women in society and explore any social and cultural understandings of female bodies and how these may impact on women's experiences in the social world and especially in relation to their health.

Chapter 2 concluded that the majority of knowledge about MS has been, and continues to be, medically based. In this chapter some of the theoretical contributions that have been developed from women's experiences and their understanding of their bodies are reviewed. Specifically the discussion identifies some of the historical and contemporary understandings of the attachments of social and cultural understandings in medicine.

Introduction

Chapter 3 discusses the role of the body as a site for academic analysis. Specifically, this chapter addresses the concerns that have faced social scientists since 1970 whilst attempting to locate the body as a site of social and cultural processes, rather than a field of natural experience. Firstly, Chapter 3 discusses the body as a subject of study and then, the issue of women, bodies and medicine.

3.1 The body as a subject of study

Chapter 2 mapped out a brief history about the origins of information about MS. The conclusions of that suggested that all historical experiences of MS had been interpreted through a medical narrative. Chapter 3 examines the body from a social science perspective attempting to explore the concept of the body. Furthermore, Chapter 3 locates key arguments which have emerged through these channels.

I know no woman-virgin, mother, lesbian, married, celibate-whether she earns her keep as a housewife, a cocktail waitress, or a scanner of brain waves-for whom her body is not a fundamental problem: its clouded meaning, its fertility, its desire, its so called frigidity, its bloody speech, its silences, its changes and mutilations, its rapes and ripenings. There is for the first time today a possibility of converting our physicality into both knowledge and power (Rich. 1972: 75)

Mauss (1936) was one of the earliest theorists in the social sciences to recognise that the body could be a site of study where social processes could be examined. In his essay on the techniques of the body, Mauss (1936) strongly argued that every kind of bodily behaviour was imprinted from learning, asserting that there was no such thing as a natural behaviour. Mauss (1936) concluded that the study of the body could only take place in the umbrella of symbolic systems. Furthering Mauss's theory of the

body first and second wave feminists recognised that the root of women's oppression related to *her* body and *her* sexuality. Mary Evans (1985) outlined that first wave feminists recognised the relationship between the experience of the body and imprinted social processes and this encouraged them to question the concept of femininity. Similarly this can be seen in the early work of Mary Wollstonecraft (1792) and Olive Schreiner (1978). For example, Wollstonecraft in 1792 described the oppression apparent in women's bodies in her notes on 'domesticated woman of privilege'. Wollstonecraft wrote (1988: 55):

To preserve personal beauty, woman's glory! The limbs and faculties are cramped with worse than Chinese bands, and the sedentary life which they are condemned to live, whilst boys frolic in the open air, weakens the muscles and relaxes the nerves.

As noted by Bordo in 1993, here it is clear that Wollstonecraft is referring to the practices of being a woman. For example, Wollstonecraft refers to woman's glory as being her personal beauty and emphasises the associated feminine sedentary living due to constricted private and public spaces for women. Similarly, Schreiner in 1911 recognises the construction of sexuality and femininity as being heavily laden with negative consequences for women's participation in the public sphere and in economic production. Schreiner suggested that '*the knowledge of woman, simply as woman, is superior to that of man; she knows the history of human flesh; she knows its cost; he does not*' drawing on essentialist arguments for women's equality. Interestingly, Schreiner recognised in 1911 that the role of women was tied to the biological self and defined within the family. She suggested that recognition of this should be valued and used as a way of liberating women, not oppressing them.

In Simone De Beauvoir's book, 'The Second Sex', she noted that the concept of woman is a social category. De Beauvoir (1949: 48) stated:

One is not born, but rather becomes, a woman. No biological, psychological, or economic fate determines the figure that the human female presents in society; it is civilization as a whole that produces this creature, intermediate between male and eunuch, which is described as feminine. Only the intervention of someone else can establish an individual as an Other.

The work of De Beauvoir recognised the central role that society plays in imprinting bodies with identities. The physical identity of the body is produced via society's cultural imprints as De Beauvoir recognised in relation to women as being described as 'feminine'. De Beauvoir's work also highlighted the concept of 'other' as determining difference, and as a locus for investigating the effects of that process.

Furthermore, the work of Mary Douglas utilised the 'space' between the physical and the social body. Douglas (1970) acknowledged the role of both the social and the physical body and the interrelationship between the 2 in the construction of female identity. Douglas (1970) theorised that the social body controls the ways in which the physical body is viewed, and therefore reflects a perspective of the wider cultural and social understandings of 'that society'. She refers to the social body as society and asserts that 'meaning' is found within the tension between the two. Douglas stated (1970: 91):

The physical body can have universal meaning only as a system which responds to the social system; expressing it as a system...Natural symbols can express the relation of an individual to his society at that general systemic level.

Douglas's reference to the use of symbols for understanding the boundaries and limits from which the physical body exists is useful to explore an in-depth analysis of experience rather than being limited to structural analysis only. Douglas's (1970)

emphasis takes a greater account of the social and physical experiences when carrying out research. As Douglas explains (1970:78):

...when anthropologists apply this technique (in reference to Bachelard's analysis in depth 1967:612) to the analysis of ritual and myth, the vertical references to physical and social experience are generally slipped in, without apology, as extensions to the total structure. Surely the account we take of the vertical dimensions of analysis must be made explicit, in order to understand the basis of natural symbols.

A key directive of second wave feminism was to examine the politics of reproduction and sexuality, acknowledge experience and difference, and develop discussions about family identities, sexual preferences and social representations (Stanley 1983). Prior to second wave feminism the study of women and the body had been limited. As Shildrick (1999:1) stated:

The status of the body within the dominant Western intellectual tradition has largely been one of absence or dismissal. Despite the necessary ubiquity of the body, and its apparent position as the secure grounding of all thought, the processes of theorising and theory itself have proceeded as though the body itself is of no account, and that the thinking subject is in effect disembodied, able to operate in terms of pure mind alone.

Early challenges around women and the body lay within the supposition that 'biologically' women had been deemed to be inferior (Spelman, 1982). Humm (1992) notes that the analysis of reproductive power and technology is of 'crucial importance' to start to unravel the patriarchal effects lodged within the power relations of institutions.

Radical feminists approached the body by creating a material history of the exploitation of women's bodies (Grosz, 1994). For example, Shulamith Firestone (1979) asserted that reproduction was the cause of women's economic oppression.

and women would be free only when control of reproduction was gained by women. Firestone's (1979) argument determined that women needed to revolt against the cultural stereotypes of biology to gain citizenship for themselves. Susan Griffin (1981) argued that pornography was expressed from a fear of bodily knowledge. Like Susan Brownmiller (1975), Griffin (1981) suggested that rape is driven by a fear of women and she traced the metaphors and practices of rape in an archaeology of male violence. Griffin argued that men have been denied a more sensual understanding of nature, which instead has been centred around women, therefore leaving male experiences of nature derelict and fearful. From this perspective the experience of 'woman' can be viewed as being couched within an oppressive and violent regime.

Martin (1989) contextualised the reproductive systems of women as being heavily inscribed with gendered stereotypes. Martin (1989) analysed the discursive practices of women's bodies and outlined how these become culturally understood as an interpretive reflection and inscription of gender dynamics. In 1991 Martin critiqued medical discourse by deconstructing medical texts on the egg and the sperm. She juxtaposed the metaphors used for both male and female physicality recognising the devaluing of the female, yet the promotion of male internal processes as being presented as more valuable. Martin (1991) called on feminists to be aware of these metaphors in the production of medical facts and to challenge them through investigation and understanding. Martin comments '*Waking up such metaphors, by becoming aware of their implications, will rob them of their power*'.

Since the inception of the study of the body as a locus for analysis, and understanding of women's experiences, there has been an emergence of study on the female body. In

this next section this discussion will be further developed focusing on medical care and women's bodies specifically.

3.2 Medical care and women's bodies

Social and cultural understandings of women's bodies can be recognised in medicine and medical situations. Understandings of women's bodies have changed over time depending on their social and cultural context (Duden, 1991; Nettleton 1995). For example, during 1700 women's bodies were described quite differently within medicine than they are today (Nettleton 1995). Attitudes to illness and women's bodies during this historical period highlight that there was little understanding about women's bodies and therefore social and cultural understandings were attached onto the medical knowledge that did exist. As Chapter 2 (section 2.1) highlighted during a historical review of the emergence of MS medical understandings have developed through scientific research. Nettleton (1995) explains this further using the work of Duden (1991) to discuss and exemplify the cultural construction of bodies and medicine. Nettleton takes the work of Duden (1991) who outlined this point after studying some medical notes from 1721. These medical notes were about a woman who had experienced 'flux' over a 13 year period. She notes that on presentation of the 'flux' in her breast (the woman) was treated with a mustard plaster after trying to lure the flux out of her body, and when the woman died some 13 years later, the 'flux' was said to have travelled from her breast to her head – the emphasis being it had moved around her body and eventually killed her.

Since this period to the current day, women's bodies have been shaped and sculptured within medical discourse and thus continue to be socially constructed as part of

medical developments. The role that medical professionals play in creating the experience of ill health for patients is an area which feminism discussed during Second Wave Feminism. Susan Sontag (1978) examined the metaphors surrounding TB, and then cancer, and said that the message provided was that cancer and TB were illnesses which were feared and surrounded in mystery. Sontag further explained that doctors often withheld diagnoses of both TB and cancer from patients and families. Sontag (1978) highlighted that this practice by doctors changed to eventually informing families of the diagnosis of illness but still withholding the diagnosis from the patient. This emphasises the powerful role that doctors hold by choosing which knowledge becomes public and which stays private. Audre Lorde (1988) in 'A Burst of Light: Living with Cancer', described interactions with her specialist as being demeaning and rooted in sexist discourse in his approach to her as a woman. She explained that her interactions with the doctor resulted in her claiming the boundaries of her own body.

The practices of medicine also encourage people to participate, and become complicit, in the formation of medical authority. For example, Frank (1995) states that patients play a certain role in reproducing the hierarchies of medical authority. He suggested that the role played by patients continues to produce and reproduce the expectations that are associated with places where medicine is carried out. Patients become bodies when they enter any medical house and as Douglas (1970) outlined that there is the inscribing of the body social and the body physical, that sets the margins for what is classified as the margin of being. Douglas, writing in 1966, recognised the limits and boundaries that are placed on bodies, specifically linking the physical body to the boundaries of social identity. Douglas recognised that the body is 'bounded', and

Douglas further asserted that this occurs through ‘symbol’ and ‘matter’ heavily engrained in culture. In Western healthcare, bodies are dependent on the key codes such as gender, ethnicity, race, class, age and disability (Turner, 1987). As Frank (1995) outlined these symbols are already waiting when a body enters a medical house.

As a starting point people engage with healthcare through a certain set of rules and regulations such as establishing themselves as patients via a health centre or hospital (Foster, 1995). Women engage specifically with healthcare through the different practices which are set up to engage with their bodies. As with most institutions, the hospital, or medical house, has clear expectations that depend on people and agencies displaying certain beliefs, behaviours and practices in order for the overarching knowledge base to succeed. The structural functioning of hospitals and medical houses are based on routine, established practise, and care (Stacey, 1997). Sontag (1991) states that any ill-health in the Western world involves a medical construct imposed in order to monitor the well and unwell body in a routine fashion. Foucault (1979: 25) outlines this point:

The body is directly involved in a political field; power relations have an immediate hold upon it, mark it, train it, torture it, force it to carry out tasks, to perform ceremonies, to emit signs.

Within the concept of biopower bodies become ‘docile bodies’ that are self regulated into the institution of medicine (Grosz, 1994). For example, the docile body can be fitted into routine, expectation and practise. For example, hospitals have beds, clinical rooms, waiting rooms and specialists all with expected and specific roles to play. It is crucial that these components work together and interplay to ensure that the

boundaries of medicine are maintained. Foucault's ideas around power, docile bodies, biopower and technologies of surveillance have been adopted by gender analysts as a site for developing understanding about gender and specifically the role of the body. Feminism was an area that Foucault did not develop himself but many of his ideas have been adopted and developed by some feminist scholars. The concept of 'Biopower' was a term used by Foucault (1979) to recognise the collision of power, knowledge and the body. This quote by Cranny-Francis (2003: 188) outlines this point:

'Biopower' is Foucault's term for the institutional control of the body in the modern state, through methods of categorisation, measurement, definition and validation. It includes practices in all institutionalised areas of life which thereby generate specific kinds of knowledge about the body – and so produce specific kinds of bodies.

Feminists have contributed to this debate recognising the pathologisation of women's bodies in the current Western healthcare system and the dominance of this in the cultural understandings of disease for women (Ussher, 1992; Lupton, 1994). Foucault based his analysis of 'biopower' from the surveillance that took place during the eighteenth and early nineteenth centuries specifically using the panoptical gaze of the prison institution (Bordo 1988). The scientific surveillance took over from the juridical control in the late eighteenth century with the emergence of scientific enquiry also at this time (Bordo 1988; Hall 1994). In essence people went from being subjects of the kings to being the objects of science. The body became an object to be manipulated and 'disciplinary technologies', as defined by Foucault, gradually formed in developing structures and practices (Nettleton, 1995; McNay, 1994). Under bio power, disciplinary technologies aim to produce human beings who behave as docile

bodies, who are productive but under the watchful eye of surveillance – for example medicine.

Bordo (1993) recognised in her reflections of her key work ‘*The history of Sexuality*’ that early feminist work was ignored mainly due to its activist approach to change rather than being theoretically grounded within academic literature. Moreso, Bordo recognised this to be a ‘faux pas on her part and her own rootedness in academic literature’ at that time. She raised key questions about the use of Foucault’s contribution to theorising the body, but established his theorising around the production of bodies and normality as being the most relevant to feminism both sociologically and politically. However, it is noted in her 1993 essay that feminism had long established these key and central ideas about the body as Bordo asserts (1993: 248):

...that the definition and shaping of the body is the focal point for struggles over the shape of power. That was discovered by feminism, and long before it entered into its recent marriage with poststructuralist thought – as far back, indeed, as Mary Wollstonecraft’s 1792 description of the production of the docile body of the domesticated woman of privilege.

Here Bordo re-establishes the emergence of feminist contributions to the body. Bordo also highlighted the use of Foucault’s concepts of normalisation and resistance. These are applied by Bordo into a feminist framework (255):

...there are thus ‘two’ Foucault’s for feminism and in some ways they are the mirror-image of one another. The ‘first’ Foucault, less a product of postmodern culture than a direct descendent of Marx, and sibling to 1960’s and 1970’s feminism, has attracted feminists with his deep and complex understandings of the ‘grip’ of systemic power on the body. The appeal of the ‘second’ Foucault, in contrast, has been his later, postmodern appreciation, for the creative ‘powers’ of bodies to resist that grip.

Bordo's (1988) earlier work asserts that in the twentieth century eating disorders such as anorexia nervosa and bulimia, and the bodies which they produce could be regarded as a parallel form of feminist protest. Bordo (1988) explained that women attempt to display agency by controlling their own bodies as the body is marked by some trauma (childhood trauma and patriarchal pressure) which is then incorporated into the body and they become ill. Bordo refers to anorexia nervosa and bulimia as being a result of this.

In the process of medicalisation women's bodies became saturated with sexuality and consequently associated discourses related to women and their bodies. Childbirth became inherently pathological, associated as a sickness for women, and women of childbearing age were viewed as being unreliable and potentially dangerous (Kitzinger, 2000; Nettleton, 2006). Women's wombs were unruly and medicine and psychiatry were called upon to regulate and surveil (see Showalter 1979). Over the past 15 years reproduction and reproductive technologies have been key sites of research for gender analysts and feminist researchers as it is an interesting position for viewing biopower and the deployment of sexuality. A recent study by Helen Jones (2006) draws on Foucault's concept "the apparatus of sexuality" (Foucault, 1980:211) for examining the position of elderly women in sex abuse cases. For example, Jones (2006) explains that rape discourses are very specific and usually 'demonise' the victim as being a 'woman who gets what she deserves' or by demonising the rapist by defining the act as 'sexually deviant and dysfunctional'. Jones recognised that Foucault's "apparatus of sexuality" identified that discourses created within power relations are always limited due to the inclusion and exclusion criteria set out within the specific discourses and prohibitions. This process limits what can be understood

and Jones (2006) applied this to elderly women and rape. She asserts that elderly women do not fit into the discourse for sex offences 'as desexed beings, elderly women stand outside hegemonic discourses of sexuality in general and rape in particular'. Jones (2006) study is an example of how discourse which is created within institutions is the vehicle for placing boundaries on what can be experienced.

Contemporary 'disciplinary technologies' around women often start with the regulation of bodies and the 'stopping' of disease in women. For example, Bush (2000) emphasises the cultural practise of cervical smears to modify and then inform women about certain aspects of their sexuality, so inscribing a particular responsibility onto them. Bush (2000: 5) noted:

The discourses embedded within the cervical screening programme widen, deepen and lengthen women's dependence on the medical profession. They also reproduce and exacerbate gender inequalities in health. Although men may also be observed and controlled by the health care system there are no national screening programmes for men...men are excluded from the surveillance of their sexuality.

This can be seen in many of the health practices ascribed onto women's health through discursive regimes and gendered medical knowledges (Foster, 1995; Nettleton, 1995). When having a baby women's bodies are regulated into a system that stipulates that women have to be docile and engage with the antenatal system for their own well-being but more so for the well-being of the baby. When women attempt to challenge in pre pregnancy circumstances it can be very emotionally difficult to take a firm stance against the current antenatal status quo. Naomi Wolf (2001) in her book 'Misconceptions' explores the experience of pregnancy and childbirth for women juxtaposing many women's experiences with the medical realities in which they cannot escape. Wolf stated (2001: 17):

But when you listen to women talk about birth, their horror stories about the medical profession are about something deeper and more fundamental than too much intervention; the thread that unites many is the experience of a telling, subtle, but distinctive lack of compassion.

Wolf recognised the subordinate system of maternity health services in America and Europe. Wolf suggests that the knowledge of maternity services in the West provides a safe, secure, environment at the cost of the mother mental and emotional well-being. For example, Wolf (2001) examines the antenatal systems in Britain and America assessing how tests are carried out on pregnant women and how 'care' is interpreted in medical discourse. Wolf recognised that hospital insurance is a key feature of medical antenatal discourse.

In recent years health research for women has focused on challenging the issues around and within reproductive health (Martin, 1989; Roberts, 2000). Currently feminists have been identifying other areas of health concern for women, such as disability and learning difficulties, establishing the multiple differences within women's health experiences (Vanselow, 2000). Ann Oakley (2000) recognised that human production provides a key site for examining the intersection of gender and the medicalised body. These current and contemporary concerns relate to the objectives set out in 1970 for second wave feminism. Forty years on, although research in this area has developed, one central concern for women is related to reproduction and how this is a site for understanding women's oppression.

It is important to note that throughout history the male body has been viewed as the 'normal' which is a key reflection of the institutions that have developed over time

and women by definition of the masculine are regarded as inherently deviant (Ussher, 1991; Vanselow, 2000). Comparisons have been drawn between the nineteenth century diagnosis of hysteria and the contemporary reproductive syndromes of Premenstrual Syndrome (PMS), post-natal depression and menopause as expressions of social powerlessness rather than illness (Ussher, 1992). Ussher (2007) reiterates the cultural and social pressures placed on women as playing a key role in hormone related conditions such as PMS. In the nineteenth century there were many women whose hysterical behaviour was interpreted as being due to a failure of the Oedipal complex (Jahoda, 1995). Also around this time hysterical women were treated as deviant and abnormal. Elaine Showalter (1987) discusses the importance of morality in the history of madness and emphasises the contextualisation of this in reference to the Victorian management of insanity underpinned by the ethos of self-control (see Showalter, 1987).

These approaches to women and healthcare have been influenced – if not commandeered – by the radical approaches during 1960 and 1970. These texts are important for thinking about women and their bodies particularly the inscription of sexuality as a discourse.

Summary

This chapter has situated the female body as a site for understanding society through how the body is experienced. Furthermore, the female body and medicine has been explored emphasising key feminist work in this area. It is also important to note that feminist thought and the body has a key relationship, even identifiable in key feminist writers during 1700. The argument of this chapter has emphasised the social and

cultural understandings of women's bodies and how these may have limited medical knowledge. This chapter has also explored some key debates for examining the body through narrative and Foucauldian approaches to the understanding the body.

Furthermore, this links to the research question which proposes to explore the lived experiences of women and MS. This literature backdrop is central for moving forward with a narrative study into the experiences of the women in this study.

Chapter 4: Conducting the research project

Methodology; research design; project influences; collection and analysis of the data

Prologue

Chapter 2 highlighted the scientific and medical knowledge base from which MS has been historically, and contemporary viewed, with Chapter 3 outlining the cultural and social interpretations that may become transferred within medical discourse specifically in relation to gender. Chapter 4 responds to both these perspectives through the journey and design of the empirical study exploring the experiences of women living with MS. These critical standpoints relate to investigating a social constructionist view of the world.

Chapter 4 outlines the process of reaching the final research framework which facilitated the empirical study. Also the ethical and practical aspects of the research process are discussed. Central to the methods and methodology of this study are feminist research practices and Chapter 4 further outlines, discusses, and develops these key components and also bring together the academic, the personal and the political methods that were influential in conducting this qualitative feminist narrative study.

Introduction

Chapter 4 outlines a brief critical approach to health research (complementing and making links with the discussion from Chapter 3 which looked at the historical, social, and cultural emergence of women particularly focusing on the power of medicine). The methods for the research are outlined situating the philosophical, ontological and epistemological elements of the thesis. These are further explained and exemplified through a discussion of the proposed data collection and data interpretation. The practical and ethical questions about the research will also be addressed throughout this section. Chapter 4 ends with a discussion of the pilot interviews carried out.

Authors note: Some sections of Chapter 4 are written in the first person due to the reflective and experiential nature of the study.

4.1: Health research and the construction of illness

The biomedical model is the key framework which underpins medicine both historically and currently (Ussher 2005; Nettleton 2006). Chapter 3 highlighted the input of feminist study which has influenced, and contributed to, the critical approaches developed around the biomedical model since its inception in the 18th Century. The development of the Sociology of Health and Illness has occurred over the past 20 years and has focused on understanding health and well being for people at various stages throughout the life course by attempting to include people's experiences (Turner 1987; Nettleton 2006). The central concerns in the Sociology of Health and Illness have centred on the emphasis of biomedicine for assessing health

and some of the limitations this may place during the creation of knowledge about certain health and illness (Nettleton 1995; Ussher, 2005). Chapter 3 provided some relevant examples of this (Martin 1989; Bush 2000).

Conclusions in critical health research have established that these are still dominant in both the scientific and cultural understandings of health with contributions being assessed in terms of their medicinal contributions to medical science (Turner 1995; Ussher 2005). For instance Chapter 2 sections 2.1 and 2.2 outlined the historical and scientific emergence of MS. This emphasised the key role of biomedicine in the construction of our current understandings of MS and also other health and illness. Within health research the outcomes or results of research have traditionally been specific in terms of providing a base from which the research findings can be situated to 'improve' a health care need or service (Bowling 1997; Bland 1996; Grbich 2000). From this stance importance has been placed on quantitative methodologies where there is a collection of numerical data (Nettleton 1995; Oakley, 2002). Even some qualitative approaches within the health care arena are still predisposed to scientific dominance in terms of relying on specific models, such as the biomedical model, for the validity of the research results (Ussher, 2005, Nettleton 2006).

The concept of the biomedical model is based on 5 assumptions that evolve from the pathologisation of the human body (Foster 1989; Nettleton 1995; 2006). Nettleton (1995:3) outlined the 5 assumptions of the biomedical model as consisting of:

1. The *mind-body* dualism which concludes that the mind and body can be treated at 2 separate entities;
2. The *mechanical metaphor* assumes that the body can be treated like a machine and approached as such;

3. The consequences of technology are overplayed and medicine adopts a *technological imperative*;
4. Biomedicine is *reductionist* in its paradigm. From this perspective explanations of disease focus on biological changes to the body neglecting the social and psychological effects of health;
5. *Doctrine of specific aetiology* refers to the explanation that all disease can be identified through a specific agent or germ.

Social constructionist challenges of the biomedical model are based on critiquing the scientific and deducible approach to knowledge production that is engrained within the biomedical model (Rose, 2006). Biomedicine can be defined as standing outside of the individual in the attempt to resolve health care problems and locating any problems in, or on, the body (Featherstone et al. 1991; Kaufman 1999; Rose, 2006). As outlined in Chapter 3 cultural values assist this process to work successfully.

Turner (1987; 1996) describes the *level of analysis* approach as incorporating 3 social levels from which the practices of health and illness can be discussed. The *individual level* examines perceptions of health and illness; the *social level* examines the social creation of disease categories and health care organisations; and the *societal level* examines healthcare systems within their political context. Research indicates that the construction of disease and illness are interchangeable concepts defined by legislation, policy, and the implementation of practise (Busfield, 2000) in Western societies. These 3 social levels can be seen as a way of creating the boundaries from which health and illness can be accessed, understood and discussed in the public

sphere. The aims and objectives for this thesis reflect some of the key challenges that need be addressed within the area of women's health and MS.

4.2 The personal becomes political

The Research Question: What are the personal and health care experiences of women with MS? evolved from a reflective research process which occurred during the lifecycle of the research study. As with the life cycle of most research projects, within the first year the principles for the research changed from the design of triangulation research methods to using qualitative methods only. Many epistemological and ontological priorities changed within this process and these will be discussed here. The following section outlines the journey of the methodology process and how and why decisions were made. The following section is written in the first person to reflect the personal and professional development occurring simultaneously.

Author's first person account of the research journey

My experiences on both a personal and academic level have directed the research throughout the PhD process. When I had received a diagnosis of MS in the first year of my undergraduate degree, I had conducted my own small scale study exploring women's experiences with MS mainly in an attempt to understand MS as there was such little information at the local level available to me (for my third year dissertation) as outlined in Chapter 1, 1.1. For example, I noticed that there were no clear directives for somebody with a diagnosis of MS to go to for help and advice. The main resource of information for people with MS could only be found in the voluntary sector but generally the medical systems in England (predominantly the NHS) did not have clear routes for people with MS.

In the wider community people with MS were involved in national and local demonstrations because of limited service provision and the lack of Government funding for drug treatments (Bland, 1999). I was involved with local campaign groups for both the MS Society and the Neurological Alliance that were challenging the lack of service provision and these issues influenced my decisions for the initial research proposal. The start of the PhD was at a time when MS was being discussed more in the public sphere particularly as several television soap operas had raised awareness by introducing characters with MS (See www.bbc.co.uk/eastenders archive). Several books had been published highlighting real life experiences of MS and outlining the lack of funding for research in this area (see Mackie 1996). It literally started to become a 'hot topic' and like most hot topics it did start to disappear from public discussion.

My first research proposal was influenced by the dominance of the approaches to health research as discussed in section 4.1. At that time I felt more comfortable to engage in these debates at that stage of my academic journey. On reflection this was shadowed by the dominance of science and the compatibility of quantitative methods to influence social change. The research question and the focus of the methodology at the beginning of the thesis were approached from a triangulation perspective of questionnaires, interviews and focus groups. I felt that a triangulation approach was relevant at this point as my research focus was to collect both quantitative and qualitative data on services for women with MS. (Triangulation refers to a use of research methods both qualitative and quantitative and the analysis is formed from both data collections (Grbich 1995)). The idea behind using a questionnaire sample

was to gauge the views of women with MS and then obtain recruitment for the interviews through this process. At this point the research topic was aimed at service provision as a way of measuring the women's experiences hence the use of questionnaire sampling to create a structural and statistical stance on the data collection (Bowling, 1997). This would be complemented with semi-structured interviews where I would follow leads taken from the questionnaire. At the end of the sampling I aimed to bring together the participants of the study and hold a focus group discussing various elements of the research. I was reading a great deal on conducting health research and my first research proposal reflected this. As suggested by Davies (1991: 32), health research aims to achieve the following:

...it provides the basic information on the state of health and disease of the population; it aims to develop tools to prevent and cure illness and mitigate its effects and it attempts to devise better approaches to health care for the individual and the community.

However, as I worked on progressing and developing the thesis I was faced with several challenges particularly about the way I was proposing to collect the data and the then the limits of the analysis. Using a questionnaire could take away the richness and depth of the data collection. I also knew from my work in the voluntary sector that 'tick boxes' and form filling created anxiety and dread in most people due to the inherent lack of coherence and sensitivity. I wanted to offer an in-depth understanding to women's experiences of MS and the original focus of service provision and questionnaire design I felt would not represent this.

This was also reflected in some of the literature I was reading such as *Teratologies: A Cultural Study of Cancer* (Stacey 1995) and *Metaphors of illness* (Sontag 1991).

These texts were looking at ill health from a social and cultural perspective and contextualising them by recognising the importance of the social construction of gender and health. Emily Martin (1991) and the cultural study of reproduction made great challenges to the discursive formation of the medical model and highlighted the gendered language and practices that were deeply embedded in the medical model of health and care. Also to work within the framework of the medical model would disable the critical aspect of the research and conflict with the ontological and epistemological questions that had raised my awareness in the beginning. Stacey (1995), Sontag (1991) and Martin (1991) were contextualising the interface of gender and illness and intuitively I felt comfortable with this standpoint. These studies had looked at the medical inscriptions placed on women's bodies and juxtaposed these with the reality of the women's lives while attempting to recognise the effects of this. In essence a deeper understanding of power, authority and discourse was where I wanted to take the research.

Also, one of the key findings in my undergraduate small scale study had shown that the diagnosis process of MS was extremely problematic and this needed to be explored further. In light of this I was also not convinced by my proposed methodology of questionnaires, interviews and focus groups. I felt it was too structured for the sensitive nature of the research because I wanted to be able to explore the women's health experiences in depth - not limit them. I felt that by presenting a questionnaire about service provision with a follow-up structured interview I was stopping the women from being able to express their feelings fully about other issues in relation to MS, such as how they felt about a diagnosis of MS or how they cope with disability on a daily basis. This development from one of a

triangulation approach to the study to one of qualitative design also helped develop the research question.

4.3: The directives underpinning the research

As the research proposal evolved it was important to map out the directives underpinning the empirical study. Once these had been verified through discussion and review with the supervisory team, and in preparation for the ethics board, the following directives emerged.

The philosophical grounding for the research is based on taking a critical approach to gender and health. Key philosophical understandings – or preconceptions- for the thesis are:

- MS is a condition that is not fully understood in medical knowledge (as discussed in Chapter 2);
- That gender relations are socially and culturally constructed;
- Female bodies are medicalised with social and cultural understandings about women (as discussed in Chapter 3);
- There is an intersection of gender and the medicalised body which can impinge on health experiences for women (as discussed in Chapter 3).

This empirical study offers an exploration of gender and ill health, specifically looking at the interaction between medical health interpretations and the medical inscriptions of being a woman. The juxtaposition of these 2 concepts, along with the influence of my experiential knowledge, frames the narrative of the thesis. The epistemology of the thesis is feminist because the research looks at women's lived

experiences of illness. Stanley and Wise (1983) outline that feminist epistemologies and research methods should reflect women's lived experiences and place greater emphasis on 'affectual rationales' (Jary & Jary, 2006). The research methods are concerned with exploring women's lived experience of illness using narrative, thus creating the characteristics of a feminist epistemology.

The thesis starts with ontological questions about the conditions of women's lives that have been diagnosed with MS. The argument within the thesis attempts to shape an alternative knowledge about MS experiences than those which are embedded in medical discourse. This will be achieved by drawing on the real life experiences of the women. The objectives for the study centre on the gains from talking to women with MS. What might their real life experiences tell us about current research practices around MS? What can their stories reveal about medical responses to women's ill health? Ontologically the research will explore how the power relationships between medical discourse and women's 'real lives' are played out in the context of:

- Women's experiences with medical professionals;
- Experiencing symptoms of MS;
- Medical response to symptoms;
- Diagnosis of MS;
- Other issues raised by the women within their narratives.

The thesis is also influenced by ethnographic knowledge gained during personal experiences with MS.

4.4 Feminist methodology and shaping the fieldwork

Feminist methodology can be defined as the following:

Feminist methodology is specifically concerned with how, or whether, knowledge produced about social life can be connected with the social realities of women in the context of any methodology that is dominated by men and that neglects consideration of the gendered nature of social life (Landman 2006:430).

There are at least twice as many women with MS as there are men so this was key for deciding to look at women's experiences only in the empirical study. There was also the realisation that women's experiences of their bodies would be different from men's experiences (as discussed in Chapter 3). For the purpose of this empirical study the concept of gender can be taken with reference to social research on gendered lives. This may include: sexuality and reproduction, sexual difference, embodiment, the social constitution of female, masculinity and femininity ideas, discourses, practices, subjectivities and social relationships. As suggested by Ramazanoglu (2003:5) the following text encapsulates the location of gender in research:

While gender can be analysed from differing perspectives and with differing assumptions, we argue that feminist knowledge of gender should include practical social investigation of gendered lives, experiences, relationships and inequalities. We see the investigation of the similarities and differences across the diversity of gendered lives as a potentially radical and emancipatory project that the term 'gender' can serve.

The above text outlines the importance of the social investigation of gendered lives.

After receiving so many letters (57 in total) in response to the advertised study it was apparent that women's experiences with MS were something that could be discussed.

Feminist methodology emphasises the establishment of non-hierarchical relationships between researcher and respondent and this can be helped through the use of reflexivity (Grbich, 1998; Ramazanoglu, 2003). Also Oakley's (1980) work around a

feminist approach to the research interview was influential. This comprised of the following:

1. The interviewer presents her own identity in the research process, not only asking questions, but also knowledge sharing where relevant;
2. Engagement from the researcher encourages more depth from the researched, creating a more honest and insightful account of the topic;
3. To develop and produce work that limits, and at times, diminishes the power relationship between researcher and researched. (The model 4a page 104 practically deals with these issues).

Reflexivity is a useful tool for recognising and subverting power relations in the research process and relies heavily on the reflective standpoint of the researcher. Here are some key points of reflexivity adapted from Ramazanoglu (2002):

- The identification of the exercise of power, power relationships and their effects in the research process;
- The particular theory of power that enables a particular conceptualization of power relations (hidden or otherwise) in this instance;
- The ethical judgements that frame the research and how these are interplayed and addressed in the research process;
- Recognising the limits of shared values and political interests in relation to the subject studied;
- Accountability for the knowledge that is produced and how accountability will be exercised.

This feminist model developed by Hogg, Bettany and Long (2000) emphasised some practical, academic and emotional concerns of the research. Model 4a was used as a research tool throughout the data collection and analysis.

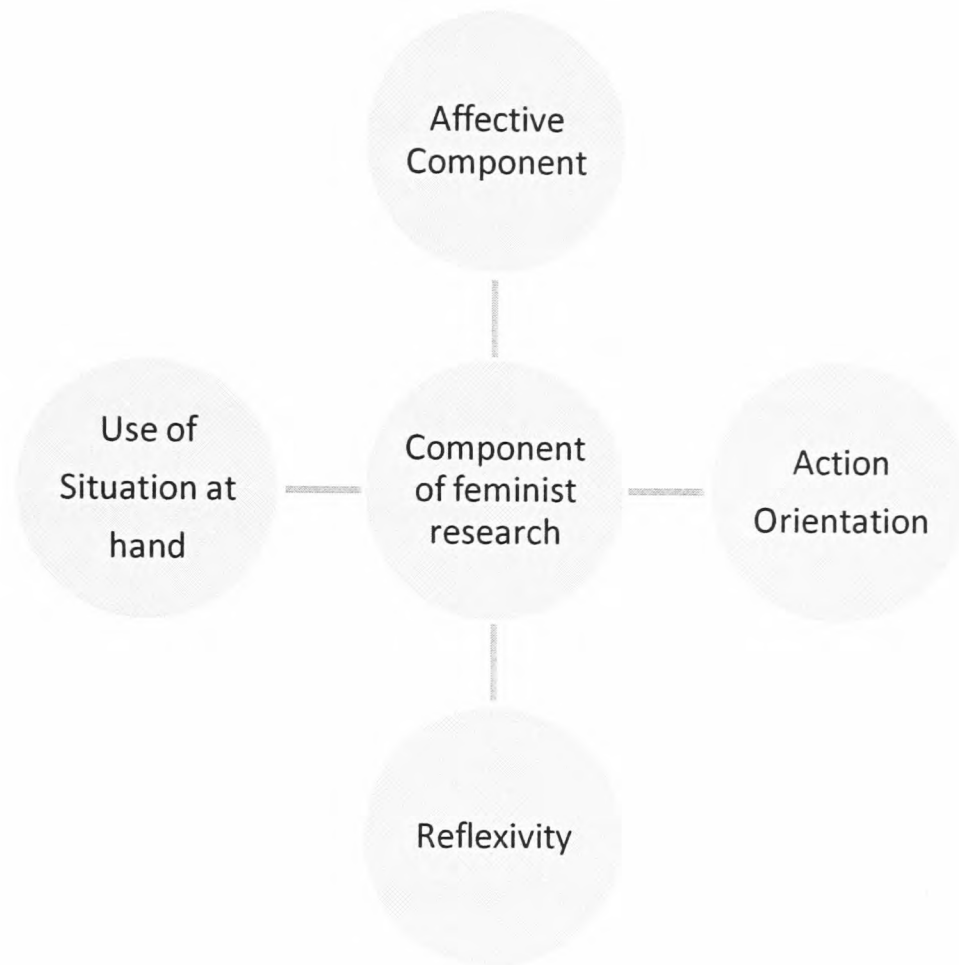


Figure 4a is a model of the 4 components of feminist research taken from Hogg, Bettany and Long (2000)

Figure 4a displays 4 key components of conducting feminist research. These 4 components relate to practices and behaviours that should be used by the researcher when carrying out feminist research. In effect these 4 components can be seen to identify the research as being feminist. The research model (Figure 4a) has been adapted to complement the research practices in this empirical study and are further discussed below.

Affective Components links to the emotional aspects within the research process.

Generally speaking feminist research advocates the role of emotion in research and

Hogg et al. (2000) identify some key attributes to the role of emotionality in research.

These key attributes highlighted by Hogg et al. (2000) are:

- recognising the affective components can be consciousness raising;
- the emotionality can be an object of study and enrich data collection;
- the recognition of positive and negative emotion in the research process enriches data collection;
- links to ethical issues such as who the research will benefit and issues of power and authority in the research process;
- overall a presentation of research results that addresses issues of power, honesty and ownership.

This is particularly important for the feminist underpinnings of this research focus and my own relationship to the research. The following key questions were reflected on throughout the research process:

- Why was I conducting the research?
- How can I prepare for the interviews and any feelings it may bring to the surface?
- How did the interviews make me feel?
- How did this impact on the data collection and analysis?ⁱⁱⁱ

Reflexivity requires the researcher to be honest and explicit about the research process in terms of the influences surrounding the project. To be reflexive throughout the whole project is an important tool and can add richness to the data collection, analyses and findings of research. Hogg et al. (2000) suggests it also important to

recognise that within reflexivity it is easy for researchers to deflect some important issues of the project through the use of the concept. Hogg et al. (2000) emphasised that if used critically reflexivity encourages some key attributes to the research process.

These are as follows:

- honesty from the researcher. This means engaging with the perspective of the researcher both personally and academically, and being explicit about their emotions and values and how these affect their view of reality – a key component of any feminist research (Grbich, 1999);
- thinking through all stages of the research process;
- being open and honest about all ethical dilemmas faced during the project;
- a non-exploitative relationship between researcher and researched^{iv}.

Use of situation at hand is the component where Hogg et al. (2000) recognised the use of any opportunistic research findings in relation to the study. Feminist researchers aim to include this information although they will keep in line with ethical boundaries of anonymity and confidentiality (Rich, 1999). (In this data collection this occurred through the telephone conversations carried out with the women prior to the interview or as I was leaving their homes at the end of the interview. I found that it helped to present a shape to the overall interview that had occurred, or was about to occur).

Action orientation is the component which recognises that the aim of feminist research is liberation (Fonow and Cook, 1991). Action orientation also refers to the use of managing to change a process similar to the principles of action research which

identifies a problem and uses the process of research to look at the change or specific outcomes (if in fact there are any at all). Hogg et al. (2000) emphasised that some researchers have even instigated change in terms of challenging dominant and oppressive discourses as a political act within a specific discipline. However, it is important to be realistic about any change when carrying out research that involves people's lives. For example, this study could also link into change as it may provide a framework for further research projects about women and MS. However it would be unfair to encourage participants into believing unrealistic outcomes for the project. On a wider spectrum, it could be feasible that this PhD research could be published or lay the foundations for some future influential research.

The 4 components of reflexivity, use of situation at hand, action orientation and affective components were used as research tools at each step of the fieldwork, analysis, and findings from this thesis.

4.5: Research design and data collection

In this section the research design is discussed. The practical components to the research such as ethical approval, recruitment, data collection, a discussion of semi-structured interviews, precede a discussion of reflexivity (linking into the model set out in Figure 4a) and the engagement of the practical aspects a researcher can apply to enhance the research process.

Ethical considerations for the project

Prior to the fieldwork being conducted a proposal of research was submitted to be assessed by the ethics board at the University of Salford (full proposal in appendix 2).

Key aspects of the ethical approval will be outlined to detail the process which occurred prior to carrying out, and then commencing the fieldwork.

1. Advertisement

An advertisement was created that outlined and detailed the research (see appendix 3). The advertisement was distributed randomly throughout the North West of England. I also placed advertisements in several women's magazines. These were chosen through price as the budget for the project was limited. Appendix 6 outlines a list of where adverts were sent for display.

2. Recruitment

Recruitment of participants took place via an ethically approved advertising campaign designed to reach as many women as possible with MS although there was a focus on the North West of England. I advertised randomly throughout England although advertising posters were predominantly distributed in the North West of England displaying posters in doctor's surgeries, voluntary groups and some shop windows (appendix 4 details a list of where advertisements were sent). I also advertised in several women's national magazines and MS websites.

There were limitations on recruitment through the ethics committee at the university who would not allow the monies for a translator, so I had to access English speaking women only. The impact of this on the research resulted in being unable to represent culturally diverse groups, such as women from Black and Minority Ethnic (BME) groups who were unable to speak English.

3. Information sheet

The information sheet was provided to each participant who took part in the study (see appendix 5 for information sheet). The information sheet outlined the proposed study and gave information about the proposed themes to be explored in the research (such as diagnosis of MS, living with MS and concerns around healthcare and MS). The information sheet also informed the reader that the researcher was a woman with MS and what the scope of the research was. Initially it had been proposed to send out information sheets to all interested participants but as the response rate was high information sheets were only given to participants in the study.

4. Consent form

The consent form was used to assure the participant of confidentiality in the study (see appendix 6 for consent form). Confidentiality in this study was explained and recorded as being:

- Details of participants will not be given to any other parties. This included name, address, and any other personal details that could identify them.
- At any point during the tape recorded interview the participant could stop the interview and the tape would be given to them.
- All transcripts and recordings will be held for 5 years before being destroyed.

The consent form was explained fully to each participant then signed by both myself and the participant.

5. Collecting the data

The fieldwork occurred over the first 2 years of the studentship including the pilot interviews conducted. (Appendix 7 outlines the timescale of the interviews). The response to recruitment was large and 57 letters were received (with 30 letters being

quite detailed) through the post from the magazine advertisements that were responded to via a PO Box. Several phone calls and emails were also received. The decision on who to interview was decided on availability, location and an attempt to represent a range of ages – although this was not applied systematically. (Initially I was drawn to a number of letters that I received due to the detail of their content about their experiences with MS. I did place the many letters into geographical areas in order to decide who to include in the study). The fieldwork expenses were included in the studentship monies and so costs were kept to minimum. It had been proposed to collect the data over a summer to autumn period so the end allocation of who took part in the study evolved through time and availability. Also once up to 18 participants had been confirmed the decision was made to end the recruitment process. The women who had contacted me but who were not to be included in the study were contacted mainly to thank them for their time in responding.

6. Inclusion/exclusion criteria

The participants for the study were recruited using a practical approach. The criteria drawn upon included the following:

- Location: An attempt was made to arrange the fieldwork so that travel could be minimised;
- Age: An attempt was made to get a range of ages reflected in the study. This was not conducted discriminately;
- Availability: Respondents were chosen if they could be interviewed during a certain time scale.

7. Participants for semi-structured interviews

The advertising recruited 18 women living with MS for potentially a series of one-to-one interviews. 16 participants ended up being interviewed due to two respondents pulling out due to personal reasons at last minute. 16 respondents were deemed appropriate after consultation with other qualitative studies that explored experience through narrative and storytelling (see Martin, 1989; Frank, 1995) and also after discussion with my supervisors. Also at the outset of the research it had been expected that some of the interviews may take place more than once due to the women becoming tired as fatigue is a common symptom of MS. The option of stopping and restarting another time was offered to each of the women interviewed particularly if they found themselves becoming upset, tired or any other reason personal to them (see section on practical concerns below for further discussion).

The interviews were semi-structured but it was also decided that flexibility could occur throughout the interview especially due to the sensitive nature of the questions. Each interview was approached with the aim of covering specific themes. The themes were around the temporal experiences of MS and focused on the past, present and future. The main issues covered were:

- The onset of the women's first MS symptoms – or their awareness that they were experiencing health problems;
- Diagnosis - what happened in this process and how long did it take?
- Present day – how do the women live on a day to day basis?
- Do they have access to health care – if so, what are the care services they engage with?
- What do they think about the future?

Practical concerns

There were several reasons why semi-structured interviews had been chosen for the data collection. The qualitative approach of semi-structured interviewing allows for flexibility in the data collection and more freedom for participants to express their stories and experiences (Grbich 1999). Practically a series of interviews may be more suitable for some or all of the participants mainly because of the following issues:

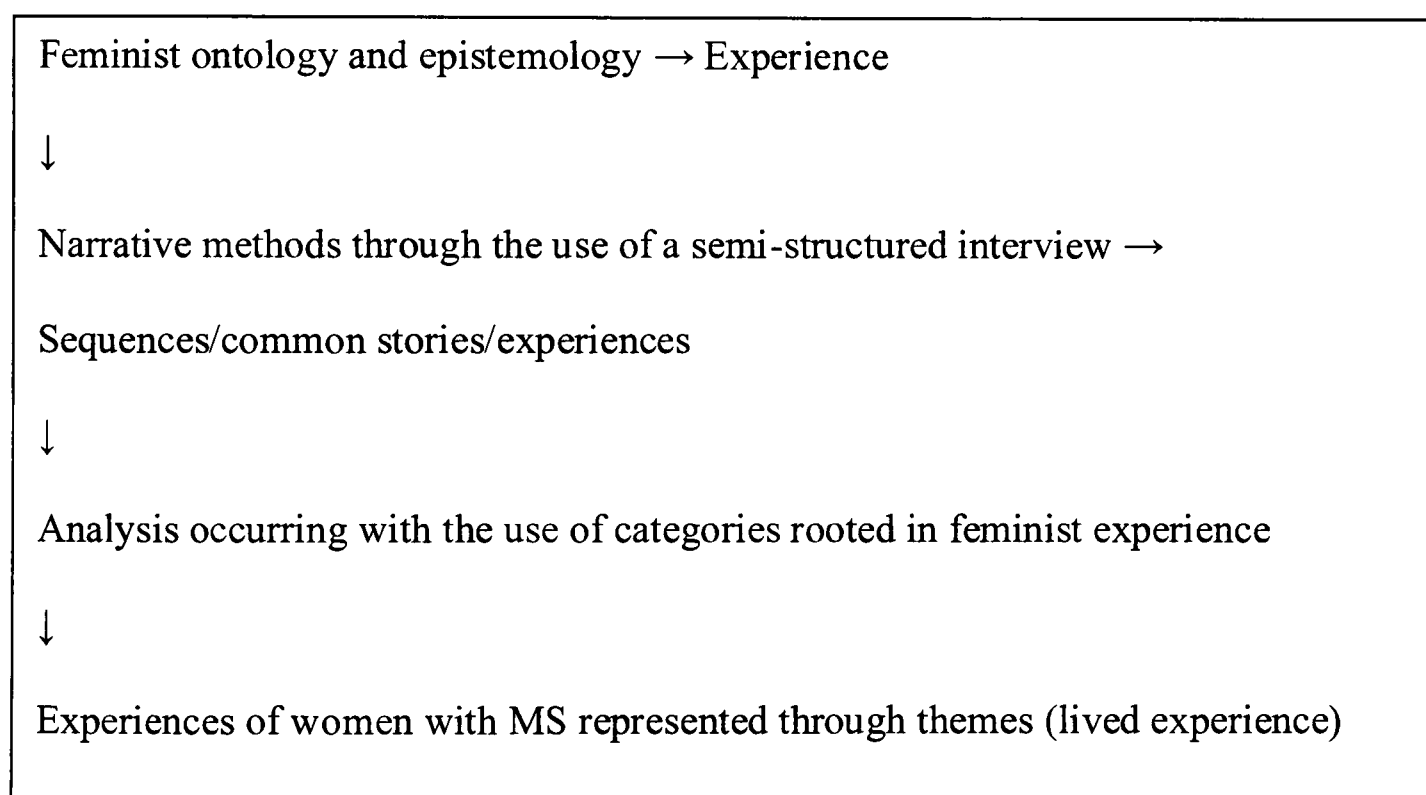
- Older people or people with disability may prefer interviews that are shorter because of tiredness (Grbich 1999; Halper. 2007);
- It gives both the researcher and the researched time to reflect on the interviews and think about issues for discussion and the direction of the research (Grinyer 2002). This complements a narrative approach to data collection;
- It may form a more relaxed and in-depth relationship between the interviewer and interviewee therefore enhancing the data collection (Gerhardt 1990; Olsson, 2008).

A pre-interview telephone conversation occurred with the women. This enabled a discussion with them about the focus of the interview, the practical side of the interview such as tape recording, discussion of the consent form, and any questions they wanted to ask. This proved to be extremely resourceful and created mutual understanding and a good atmosphere before the interview schedule. This was also informed through the pilot interviews (see section on pilot interviews and reflections page 120 for further discussion).

4.6: Interpreting the data collection

This section will discuss and set out the analysis of the data collection. Firstly, there will be a discussion on the usefulness of narrative analysis in this study. Gilbert (2002) argued that there is no set way to conduct a narrative study and suggested that the primary goal 'is to understand from the perspective of the teller'. Figure 4B highlights the conceptual framework designed for this qualitative feminist narrative study.

Figure 4B displays the conceptual framework of this qualitative feminist narrative study



Feminist approaches and narrative analysis

Narrative analysis can be grounded within a variety of conceptual frameworks influenced by phenomenological and constructivist approaches to research (Gilbert, 2002). Narrative analysis is also used amongst critical researchers within the social sciences, particularly within feminist approaches. A feminist standpoint epistemology

in research, as discussed earlier, advocates the exploration of gender. The gendered experiences of health have been acknowledged within social research and are a way of recognising the material conditions and the symbolic discursive processes of social life (Martin, 1989; Ussher 1997). For example, it is important to explore and theorise women's narratives particularly in health research as the research can reveal gender and ethnicity inequalities whilst defining identity and agency within the framework of a person's own understanding of experience (Ussher 1997). Importance would also be placed on my own subjective experiences with the research project and would be seen as being beneficial to the depth and richness of the data collected. In this sense, narrative and self are inseparable within the role of reflexivity, being central to the understanding and 'making sense of' narratives of the self (Ochs & Capps, 1996).

Narrative as a research tool can provide the following depth to analysis:

- Exploration of experiences;
- Expression of experiences;
- Representation of experiences;
- And provide meaning and understanding to experiences.

Using narrative as a research tool allows for an exploration of the relationship between ill bodies and society, specifically, medical institutions. Frank (1995) exemplifies this within illness narratives constructed within the domain of experience, reality and cultural conceptions of chronic illness. Frank (1995) identifies several narratives that explore the cultural ideologies of ill bodies and Frank uses these to reconstruct the embodiment of illness drawing on a variety of illness narratives. As Frank stated (1995: 22)

“The stories we tell about our lives are not necessarily those lives as they were lived, but these stories become our experience of those lives. A published narrative of an illness is not the illness itself, but it can become the experience of the illness”.

Franks use of narrative as a research tool provides a platform from which stories can be analysed, presented, and understood. The analysis framework by Frank was a useful influence when deciding how to present the narratives, and for linking the women’s narratives that said similar things about MS.

Also the use of storytelling in research influenced the analysis of the data collection which is detailed below. The approach of storytelling as a research method can be useful especially when conducting a study that is embedded in a feminist framework. Reissman (2001) recognised that storytelling does not assume objectivity about the research encounter and by contrast privileges ‘positionality’ and ‘subjectivity’. In this empirical study this concept of privileging ‘positionality’ and ‘subjectivity’ compliments, and works in conjunction with, the feminist model discussed in 4.2. Storytelling is a shared event that is produced within a particular cultural and social context – with these latter details being essential to the interpretation (Reissman, 2001). Skultans (1999:322) recognised that illness narratives revealed ‘deeply historicized and social views of health and illness’ in a study she conducted which looked at post-Soviet women’s patients’ accounts of hardship in Russia. These accounts of hardship experienced by these women were not tracked in the physician’s accounts of their health problems. Skultans (1999) study highlighted the importance of listening and recording the views of people experiencing ill health, as physicians are trained to record specific information, which is usually scientifically and medically based.

All narratives or stories are located in a certain time and place and adapt according to the circumstances of that particular history. In 1980 Mills recognised that ‘personal troubles’ are linked to both history *and* individuals. As Laslett (1999: 392) outlines:

it is appropriate to think about personal narratives as emphasising individual and collective action and meanings, as well as the social processes by which social life and human relationships are made and changed.

Semi-structured interview

The use of formal structure placed on research immediately shapes, or attempts to control, the meaning of the topic being studied and to a certain extent this happens in all research encounters. People need and want limits placed on a research encounter such as how long the interview will take? What is expected of them? Are there any specific questions that need answering? How a structure was negotiated in the interviews and any effects these negotiations may have had on the data collection is discussed in this next section alongside with a pilot study which assisted in defining the details of the data collection process

The notes and letters received in the recruitment process identified key themes emerging (building on previous findings from a small scale study conducted as an undergraduate). These specifically focused on many of the women feeling aggrieved at the long diagnosis process, the wait between the first symptoms and a medical confirmation of MS and also a sense of not being believed by doctors about their symptoms. The format of the interview was set out using questions that focused on the following journey of the women’s stories:

- History
- Present

- Future

The questions used for the interview were:

- History

1. When did you get a diagnosis of MS?
2. When did you first experience MS?
3. How did you feel about MS, before diagnosis and after?

- Present

1. How do you manage MS on a daily basis?
2. What impact has/does it have on your life?
3. How do you cope with living with MS and do you think it has significantly affected you as a person?

- Future

1. How do you see the future with MS?
2. Do you think that MS is helped through medical procedures/treatments?
3. What do you think could be improved for people living with MS? Do you think it is different for women?

Constructing the data analysis

Once the practical aspects of the methodology had been organised (as outlined in section 2) the structure for the analysis was designed. As 16 interviews provided a lot of data to be analysed a two tier data analysis was used. A two tier analysis addressed key themes and findings and also provided depth and exploration of the lived experiences. The first tier of analysis looked at the information given by the women in relation to the specific questions asked during the interviews. In some interviews

these questions were not formally asked as they had been answered by the women through the process of recounting their experiences with MS. These issues were about the past, present and the future and were included in all the data collected. This mainly concerned the following:

- First experiences of MS;
- How this was coped with;
- Any medical responses to these symptoms or subsequent ones;
- Current coping with MS;
- Family and personal relationships;
- General medical experiences past and present;
- Aspirations for the future;
- Any other key themes raised in relation to the above.

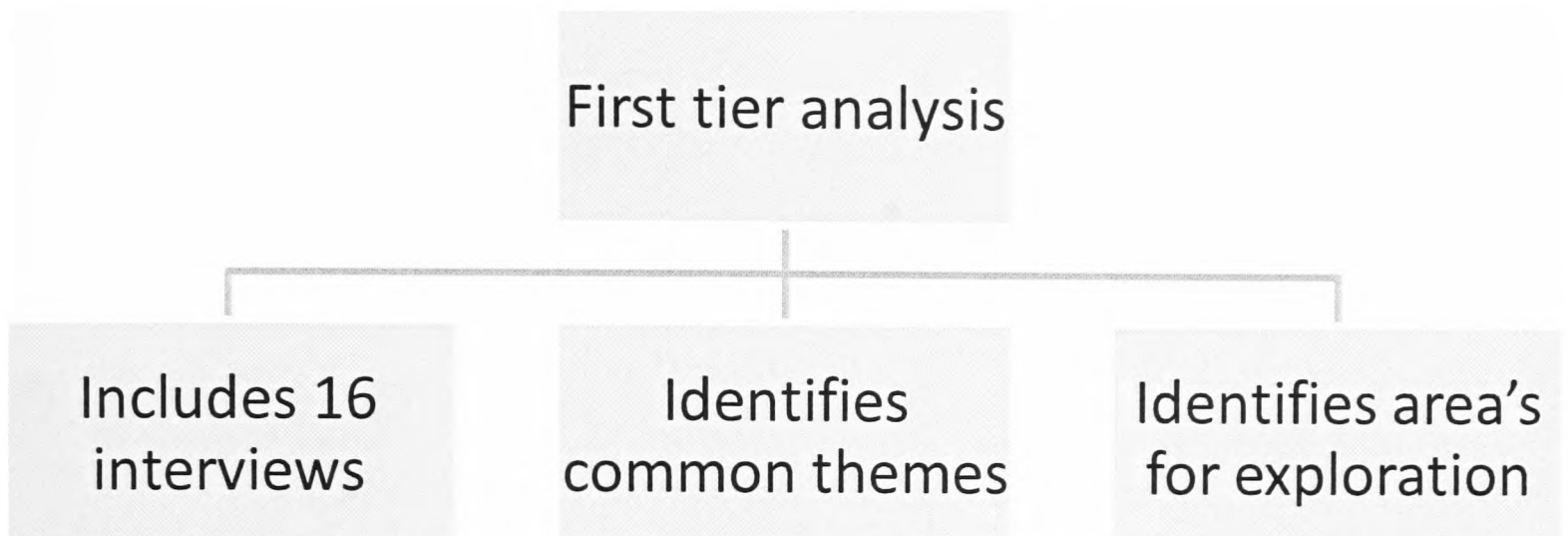
The first tier of analysis allowed for analysis of all the interviews to be included. 16 interviews and transcripts held a lot of data collection. The themes were identified drawing on the commonalities in the stories that the women revealed. A structure influenced by the work of Huberman (1989, 1993), who conducted a lifecycle study of 160 teachers, was used. Huberman (1989, 1993) mapped out in sequence the themes from each interview. Huberman was working with a large amount of data, and was also drawing on other methods within his study, but his use of sequences narratives over a life cycle were useful when considering the data analysis. Taylor and Littleton (2006) suggest that it is useful to look for patterns in narratives when you are analysing a number of research interviews. They suggest that 'common stories' within multiple narratives is a legitimate form of examining the social phenomena in question. This also encourages the researcher to continue to re read the narratives in

order to explore the differences within the 'common stories'. This is also a useful strategy when the narratives are being analysed within a wider context. Also, Peters, Jackson & Rudge (2008) maintain that feminist narrative research methods empower the teller, and allow the researcher to explore the relations of power that impinge on women's lives. They comment (2008:375):

A well-rehearsed point from a feminist perspective is that women's stories, mostly oral, have been subsumed and silenced by the written narratives of patriarchy. To overcome this, it is important for feminist research to recuperate women's stories through researched accounts of their everyday lives.

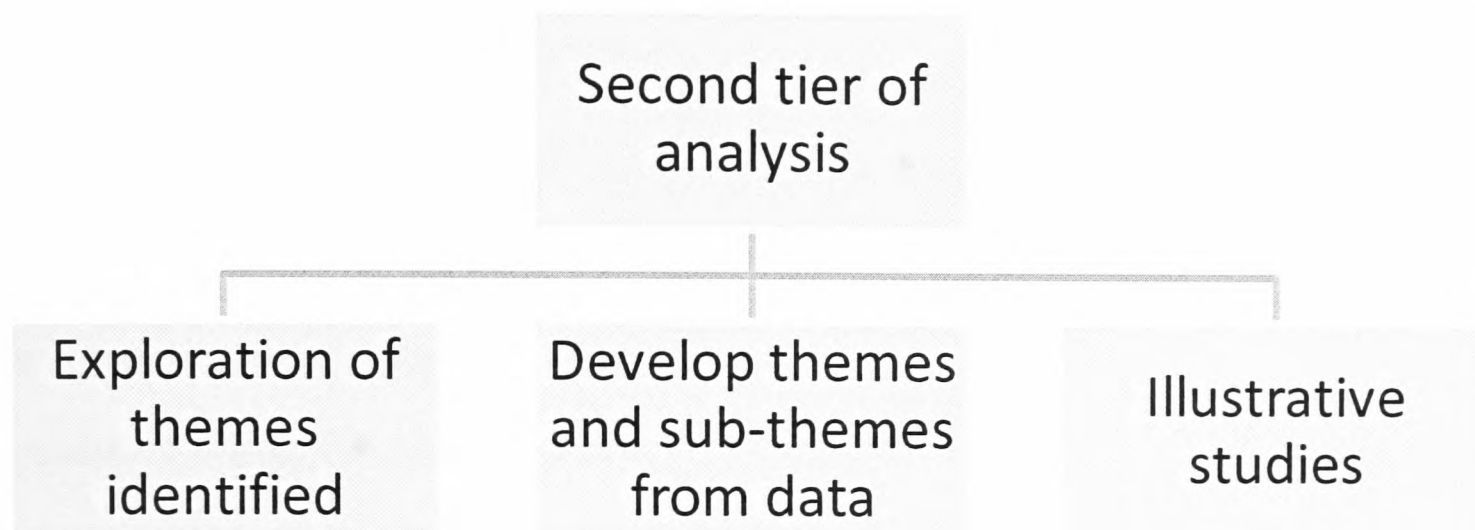
In reality when the analysis was taking place there were noticeably key common themes within the women's stories. The collection of themes in the data analysis were directed by the information and stories provided by the women during the interviews. The commonalities within the stories were more than coincidental and these common experiences 'said something' about women's experiences with MS.

Figure 4C of first tier analysis



The second tier of analysis focused on looking in-depth at the narratives and exploring and contextualising the women's stories. Some of these in-depth explorations were presented as 'illustrative studies' and focused on the lived experience of MS for women based on their narratives. Both tiers of the analysis were conducted on all the interview data although the illustrative studies were used to offer a more contextual exploration of an individual story (the analysis chapters show some of the women's illustrative studies). Also, throughout the analysis chapters key narratives were used to enhance a theme.

Diagram 4D of second tier of analysis



The interview data was analysed by firstly making transcriptions of the interviews. The philosophy of Hermeneutics was also influential when shaping a framework for analysing the narrative, both in the first tier and second tier of presentation of the findings. Hermeneutics philosophy generally refers to the conduct of interpretive research (Crotty, 1998). The adoption of the hermeneutic circle specifically (Geanellos, 1998) can offer an in-depth interpretation that along with reflexivity (feminist model used fig 4.2) helped to address any tensions from my own relationship to the data. Kearney (1991: 277) outlines the use of hermeneutics interpretation:

Ricoeur's famous phrase 'the symbol gives rise to thought' expresses the basic premise of hermeneutics: that the symbols of myth, religion, art and ideology all carry messages which may be uncovered by philosophical interpretation. Hermeneutics is defined accordingly as a method for deciphering indirect meaning, a reflective practice of unmasking hidden meanings beneath apparent ones.

Ricoeur's (1974) approach allowed for an interrelationship between epistemology and ontology – a space which needed to be acknowledged in the analysis. This also supports the development of an inter subjective knowledge which emerges through the interdisciplinary approach of the empirical study. One of the advantages of drawing on a hermeneutic framework is the ability to adapt the model to suit the project. As the methods employed for the analysis were not hermeneutic, but were influenced by some hermeneutic strategies, a hermeneutic influence was suitable. For example Wiklund, Lindholm et al. (2002) drew on the work of Ricoeur for a study looking at the concept of caring although adapted his approach to suit their own epistemological and ontological challenges, similarly adapted for this empirical study. The influences of Ricoeur in this data analysis were as follows:

- Naïve interpretation – this is a general sense about the narrative or story. In this case a general understanding that women with MS experience problems with receiving a diagnosis of MS and have problems being taken seriously when they present their initial symptoms of MS to a medical professional. Most of the women described being dismissed at this stage of their MS experience;
- Narrative structures – this allows the interpreter to read the text and organise the plot of the story that is being narrated. For example, all of the women told of being given or offered anti-depressants for 'MS symptoms' rather than being offered further investigation. They were questioned over whether they had imagined their symptoms, or misread them, or were offered medication to calm them down as they appeared anxious. As noted by Wiklund & Lindholm

this second reading confirms the first naïve reading but adds new dimensions to the interpretation;

- Deep structures in the text - this reading of the narrative looks for metaphors that are usually formulated by the researcher to give a deeper reading and explanation of what is happening in the text. (For example, each chapter presents themes to provide understanding about the lived experience of MS).

This provided the data analysis with an interesting and original interpretation of women's stories with MS because the 2 tier approach allowed for some key stark inequalities to be highlighted whilst still exploring in-depth illustrative studies from some of the interviews.

The interpretation of the data collection started in the interviews. The interpretation continued through listening to the taped interviews and transcribing them. Reissman (1993) recognised the process of interpretation as 'labour intensive' requiring several processes of listening to the tapes, reading and re-reading the transcription in order to present the participant's narratives and themes. Overarching all of the processes were the impressions each of the women had left with me. The combination of listening to the interviews and reading the written text evolved into the analysis chapters. The process of interpretation was informed by several interlocking influences that encapsulated my personal, academic and intuitive experiences and understandings.

Table 4.1 outlines the process of the data analysis.

Table 4.1 outlines the process that occurred in the data analysis.

Stage 1	Conducted semi-structured interview.
Stage 2	Following each interview I wrote a synopsis based on my immediate observations, thoughts and feelings.
Stage 3	Each tape was transcribed verbatim. Several photo copies were made of each interview transcript.
Stage 4	I read and listened to the interviews several times making notes of the women's stories.
Stage 5	The development of categories/sequences occurred through the common stories that the women told.
Stage 6	These themes were highlighted in colour coded categories on the women's transcripts where relevant. The several copies allowed me to develop each theme on a separate transcript. This helped section the narratives up more clearly.
Stage 7	I organised categories of themes in a chart.
Stage 8	The development of the categories organised the narrative chapters of the thesis Chapter 5 – 10.

The women's stories predominantly said some key things about women with MS.

Listening to the women's stories of their MS experiences were powerful and moving.

The common experiences were around the following themes:

- Similar experiences with health professionals at the onset of MS symptoms:
- Similar experiences around understandings for the onset of their MS symptoms:
- Similar problems that occurred whilst living with MS on a day to day basis:
- Some similar issues that were attached to age and their experiences with health and illness over time.

Authors Note: the following section of pilot interviews and research reflections are written in the first person due to the intimate nature of the process of interviewing.

A pilot study of women with MS was organised to prepare for the interview process.

Methodologically, qualitative research structures such as semi structured interviews

do not need detailed pilot studies in terms of justification for their usage (Grbich, 1998; Bryman, 2001). It is quite common to use pilot studies for questionnaire design and coded questions on surveys but piloting interviews can help organise the interviewer (Bowling, 1999). During discussion with my supervision team it was suggested that it would be beneficial to 'practise' interviews with women unknown to me rather than using contacts already established through my voluntary work. Access was gained to 2 women unknown to me through a connection at the MS Society. The following is an account of what 'happened' in the research situation.

First interview (Interviewee A called Rosie)

The participant was a woman aged 52 called Rosie with primary progressive MS. Rosie showed visible signs of disability the most obvious being the use of a walking stick. I had waited to discuss the study with her until I arrived at her house although on reflection some more in depth discussion on the telephone would have helped to start the interview quicker as we spent a good half an hour discussing issues of the project. I made a fieldwork note of this for the next interview. Before the interview started I discussed the research with Rosie and asked her if she minded if I tape recorded the interview. I gave her a consent form and discussed the ethics of the research with her. I did not start the interview until all questions had been asked and Rosie was comfortable.

The interview lasted an extra hour after the initial discussion of the project. This was discussed and arranged with reassurance from Rosie that the time and focus of the interview was comfortable for her.

Second interview (Interviewee B called Janet)

The participant was a woman aged 35 called Janet with secondary progressive MS. Janet showed visible signs of disability and mainly used a wheelchair. We had chatted extensively on the telephone prior to the interview and this had laid the groundwork for a more comfortable and easy start to the interview. For example, on the telephone we had established the aim of the interview and what the goals and objectives for the study were. I had already explained the study and what the interviews were aiming to do and this proved more productive than the previous interview. When I arrived at Janet's house the interview started almost straight away – we filled in the consent form and I started the tape recorder - and the interview lasted for an hour and a half. As with the previous interview, Janet led the timescale of the interview.

The questions were used to get the interview flowing although once started I found it easier to think in terms of their temporal experiences of history, present and future and each of the women took the lead with deciding on the order of the story. There was also a natural trajectory that the women took when describing their experiences. They started at the beginning of their MS symptoms and worked through the significant events in relation to their own experiences. Once the interview started I did not have to refer to the questions which I had prepared to take with me as they were being answered by the women and their experiences. For example, the nature of the interview is extremely sensitive and I did not want to halt an emotional conversation to ask a question if the interviewee was telling a story. This occurred during both interviews and the data would have been interrupted and disjointed had I tried to intervene into the narrative of the story. The questions can be used as a guide to issues that I wanted to cover but mostly these were answered through the women's

narratives and as part of their own experience. This confirmed for me that my preconceptions about the research – and the issues I had felt were important – were a relevant trajectory to explore. The rich data that came out of these two interviews framed the emotional and intuitive experiences of these women. In both interviews themes developed and I could start to establish and build links into the use of narrative and storytelling as a research tool for understanding experience.

Research reflections

The pilot study made me aware of the practical side of the research and how I could prepare for each interview. (For example, ensuring that I had spare batteries for the tape recorder, and a diary and pen for any extra note taking). On the first pilot interview I had not had a detailed discussion with the interviewee until I turned up at her house. This was time consuming and I could see that she was getting tired towards the end of the interview. I realised that ‘housekeeping’ issues could be discussed and resolved in a phone call before the visit happened.

In terms of the analysis I realised that I could develop a conceptual framework that did impose a structure on the interview format. This was developed through my own life and medical experiences and it was important for me to recognise this, but to also include this in the research encounter. I was always honest and open throughout the research process about having MS and in many ways this enhanced the women’s storytelling.

Finally the pilot interviews were useful in setting up and defining the template for the interviews and eventual analysis for the research.

4.7: The data collection and participants

Overall 16 interviews were completed in this data collection. Many letters were also received, with 4 of the letters, offering great detail around the temporal experiences of MS. In order to include the data collection which was of great value when looking at the specific themes of the research the data collection is organised as follows:

- Key themes were developed from the interviews conducted with the women. However the analysis was influenced by a number of factors, such as research methods and tools; ontological and philosophical stances; subjective and experiential standpoints including some of the letters received but not fully used in the study, my own experiences, and my own work with people with MS;
- These key themes are presented in the seven analysis chapters;
- Each chapter explores the themes using an exploration of some key interviews and narratives;
- Some key interviews were explored in-depth to explore the complex dynamics of the lived experience.

Data collection overview

After each interview a synopsis was written about each interview. This process was the start of the analysis and started the development of the themes that are presented in the analysis chapters. The synopsis of each woman was written again (or added to) after the transcription of the interviews and below is the end result of that process.

Synopsis of face to face interviews including a short biography

Louise

Louise is 21 and has recently been diagnosed with relapsing remitting MS. Louise has had one serious attack when she was 20 which was dealt with straight away and led to an immediate diagnosis. Louise says that the MS nurses have been ‘absolutely brilliant’ and have provided her with an invaluable amount of information. Louise has also started a treatment plan for MS and has opted for Beta Interferon. Louise recognises that she was offered this because of her age and her lack of disability. She says that she is worried about the future and finds it hard to discuss her fears with her family. Louise says they have been quite dismissive of her diagnosis and avoid the subject. Louise relates this to long term problems within the structure of the family and says she is not at all surprised. One of her sisters is a nurse but refuses to acknowledge Louise’s diagnosis of MS. Louise says the biggest thing in her life will be to move away from her family as she thinks they will make her illness worse. Louise admitted that she was still grieving for her health and has not yet accepted her diagnosis of MS – or indeed what this meant to her.

Jesse

Jesse is 26 and has relapsing remitting MS. She was diagnosed at the age of 22 and is taking Copaxone (please see appendix 1 for BNF description) which is a self inject treatment. Jesse relates the onset of MS to the break-up of her long term relationship and her parents’ disapproval at finding out she was a lesbian. Both issues happened at the same time and Jesse said it was ‘all too much, my body just collapsed’. Jesse believes that the beginning of MS is psychosomatic and she thinks that she would be better having counselling not drugs. However, she says she will take the drugs ‘just in case they work’. Jesse finds it hard to come to terms with her changing body and

comments that sometimes she feels like she has lost herself. She realises she is going through a period of adjustment but thinks that MS is too 'blurry' to get a handle of. Jesse is hopeful for the future.

Sammy

Sammy is 30 and has relapsing remitting MS. Sammy has three children and was diagnosed with MS two years ago when she was 28 years old. Prior to this she had been on 'every anti depressant going' as she says she was made to feel she imagined her symptoms. Sammy said that being diagnosed was a relief for her as she had something to deal with rather than feeling frightened and confused by symptoms that had no name. Sammy is a single parent and sometimes finds life difficult with MS. She thinks that she has MS because of her stressful life and life history. Sammy talks about her family and how all the relationships are unhealthy-something she won't repeat with her own children. Sammy finds doctors and health professionals contradictory and judgemental. She thinks they ignore her because she is a single parent and on benefits. Sammy says the future must be brighter and she is hoping to retrain for a good job that will provide security for herself and her children.

Josie

Josie is 32 years old and has relapsing remitting MS. Her first experience of MS was 'very aggressive', by her own description, and she was hospitalised for three months. Josie was aged 23 when she experienced this and her mum had recently died from breast cancer. Josie believes that the stress of her mothers' illness contributed to the onset of MS and the aggressive nature of her first attack. Josie experiences MS on a daily basis and has a lot of pain. She has a deep distrust of the medical profession as she has had several bad experiences at the local level. Josie believes that neurologists are not interested in listening to patients and offers several of her own experiences to

confirm this. When Josie was diagnosed with MS her husband left her. Josie explains how she copes with MS on a daily basis and how she copes with being a parent to two young children – she has since married somebody new and says he is very supportive of her MS. Josie highlights the lack of support and understanding from the healthcare professionals across the board and says she feels like she is ignored.

Liz

Liz is 35 years old and has relapsing remitting MS. Liz recalls her first symptoms being when she was a teenager although she did not get a confirmed diagnosis until she was 31. Liz manages her MS symptoms but has had several unpleasant experiences with health professionals. She has several stories to tell about her interactions with doctors. Liz believes that MS is related to stressful events and tells her own stories of life events that she links directly to MS symptoms. Liz says that MS entered her life when her parents marriage ended and she realised her dad had been assaulting her mum. Liz practically manages her life and symptoms on her own and admits that she does like to be in control of her healthcare and her body. Liz is married but does not want to have children. She says MS is a good excuse not to have them and her husband is worried about the responsibility.

Alison

Alison is 39 years old and has MS. She is unsure of the type of MS she has as she says she has been given a lot of conflicting information from various doctors. Alison has distrust in medical professionals although she admits that she likes to ‘keep MS to herself’. Alison first experienced MS when she was living in Puerto Rico with her husband and two small children in her early twenties. Alison’s husband died of cancer and she says this preceded her first attack. Prior to this Alison says that she had ‘run off’ to Puerto Rico with her husband as both their families disapproved of the

relationship. Alison relates her MS as being a release from her pain and grief and although she is now married again Alison believes that having MS allows her to not think about the death of her first husband. Alison explains the bodily experience of MS as being very frustrating and offers several examples of this. Alison finds it difficult living with MS and is in a lot of pain.

Rebecca

Rebecca is 46 and has primary progressive MS. Rebecca started with MS when she was twenty and was diagnosed within three months of her first attack. Rebecca had access to private healthcare and she suggests this explains her early and immediate diagnosis. Rebecca currently works for the NHS in London and holds a senior position; something she feels gives her access to 'good' neurologists. Rebecca relates her diagnosis of MS to a deeply troubled and controlled upbringing. Rebecca talks about her strange relationship with her mother and how she feels the lack of a loving household 'made her physically ill'. Rebecca talks about her experiences of healthcare and thinks that neurologists traditionally do link MS to a psychiatric disorder and talks about her experiences of this. She also talks about how her mother defined her as 'mad' and refused to see her in hospital when she was initially diagnosed with MS. Rebecca talks about her life in terms of traumatic events and believes that there must be a link to the onset of MS. Rebecca also believes that MS has given her something to focus on rather than thinking about all the 'bad things' in her life.

Emily

Emily has primary progressive MS and is 42. Emily has visible disability which she says is progressing quickly. Emily was diagnosed with MS when she was 38 after battling with doctors for about 10 years. Emily is in control of her healthcare and

knows what works for her. She has adjusted to her new body although it is still a struggle for her. Emily misses her independence although she has found a new sense of freedom that she attributes to MS. Emily is divorced and has 2 children. Emily enjoys being a single woman and has found companionship with a close group of friends-most of who have MS. Emily says that MS has brought many positive things into her life.

Jenna

Jenna is 42 and has secondary progressive MS. Jenna first experienced MS as a teenager and was diagnosed when she was 32. Jenna has a fast progression of disability and has had to adjust her life significantly. Prior to diagnosis Jenna was a career woman and had a high status job in management. Jenna is unable to work now and finds this frustrating. She is cared for full time by her husband and they have two children. Jenna says that MS has engulfed her life and changed all her relationships. She finds her loss of independence the hardest thing to cope with as she has no control over anything that happens to her. Jenna says her life is very different but she does emphasise some positive aspects that MS has given her such as painting and artwork.

Suzanne

Suzanne is aged 45 and has relapsing remitting MS. She is married and has 2 children and both of them are entering adulthood (one was at college and the other starting university). Suzanne has found that MS is dealt with insensitively in terms of medical support and recalled several stories at the hands of doctors. Suzanne was a very proactive woman in terms of her personal understanding of MS and how she engaged with medical professionals.

Gill

Gill is 54 and has relapsing remitting MS. Gill was diagnosed when she was 45 although remembers going to the doctors in her twenties with MS symptoms. She was sporadically given tranquilisers and anti depressants for her symptoms until she had her 'worst' attack prior to her diagnosis. She says the neurologist at the hospital was 'horrible' to her and talked to her like she was stupid. Gill is very angry and distrustful of doctors although emphasises that 'some are nice'. Gill says that her husband left her because she had MS and he didn't want to look after a disabled woman. Gill says that they had been unhappily married for years and had only stayed together for the children. Gill says that having MS has changed her life for the better and she has been given another chance at life. Each day is a challenge for Gill but she says she wouldn't change it even if she could.

Linda

Linda is 57 and has primary progressive MS. Linda has visible disability and is unable to work. Linda was diagnosed when she was 44 almost immediately at onset of disease. She is married with three children and is a proactive campaigner for people with MS. Linda relates MS to genetics and traces the disease back in her family history. Linda has a lot of negative things to say about the medical profession and the treatment of MS but feels that she does a lot to bring awareness around the issue through her voluntary activities. Linda accepts that her body has changed and manages to adjust. She took her diagnosis of MS as a new lease of life and has travelled around the world extensively.

Alice

Alice is 67 years old and has secondary progressive MS. She started with MS when she was 35 after experiencing optic neurosis, but did not get a diagnosis of MS for ten years. The diagnosis occurred when she had a serious attack and lost the use of her

left leg. Alice says this is the first time she demanded medical attention in relation to her symptoms and she was diagnosed with MS almost immediately. She was initially diagnosed with Relapsing Remitting MS and links this to her father as he had suspected MS but died before a diagnosis. Alice has had a slow progression of disability over a thirty year period. Alice links her diagnosis of MS, and the onset of MS, to an emotionally stressful period of her life. She had been married to an Indian property developer for twenty years with one child and said that the illness made her reassess the state of her life. Alice talked about the cultural and social pressures of being in an interracial marriage and suggested that her diagnosis of MS helped her escape from a life she was desperately unhappy in. Alice also relates MS to being psychosomatically linked to her life experiences and pinpoints particular events in her life to MS symptoms.

Doris

Doris is 67 and has secondary progressive MS. She remembers experiencing symptoms when she was 20 although she got diagnosed when she was 40. Prior to this Doris had been treated for depression and anxiety related disorders. She recently stopped taking tranquilisers as she felt they were doing her 'more harm than good'. Doris is divorced and has 3 children. Doris believes her divorce triggered her worst attack which led to her diagnosis. Doris had support from 2 of her children although the youngest sibling finds it difficult to deal with. Doris says that she is angry with her body for not working properly although she is a lot better now and is more accepting. Although Doris relates her MS to traumatic events in her life she does believe that it has enhanced her life. Doris says that MS has made her think about her life and make sense of some of the events and relationships.

Doreen

Doreen is 69 and has a diagnosis of MS. Doreen lived with MS for many years before a diagnosis was given to her. Doreen spent many years visiting her local GP with symptoms of MS but feels that on reflection she wasn't treated very well. Doreen has had a fractious relationship with her husband over the years and she says he has been unsupportive in terms of her health needs. Doreen has 3 children and says she leans on them at times for support.

Iris

Iris is 71 and has had MS for as long as she can remember. Iris does not believe there are different types of MS and says 'you just get better or worse'. Iris can remember being 21 and getting sore eyes and funny vision. Iris says 'in those days doctors used to say it was all in your mind'. Iris has several stories to back up these claims. Iris thinks that MS is 'one of those things' and 'you have to get something'. Iris says that MS has brought a lot of fun into her life and she has met the most amazing people along the way. She says MS allowed her to be clumsy, dizzy and forgetful! Iris has been married for 50 years and has 4 children. Although she is visible disabled Iris manages her symptoms along with her husband's help. She says he has changed over the years and he is a lot kinder and understanding now. Iris is happy having MS and says that she has lived with it most of her life that she has forgotten what her 'other' body was like.

Summary

This chapter has outlined the methodological approach of the thesis. Section 4.1 outlined a critical awareness of health research particularly recognising the implications associated with the biomedical model. This was an important aspect of the research because it situates the research within a framework that would not

usually be associated with other research about MS (see literature review). Also as chapter 4 looks at a history of women's bodies it was important to start the methodology chapter making a reference to a critical approach to healthcare (although this is incorporated throughout the whole thesis).

Section 4.2 of this chapter lays out the methods for the research and fieldwork placing particular emphasis on the importance of the practicalities associated with research practise. The use of reflexivity is discussed and applied to the structural needs of this piece of research – extremely important given the subject area being studied. The experiential is highlighted here as this is central to the workings of the whole thesis. The philosophical, ontological and epistemological positioning of the thesis is allowed along with relevant questioning. Narrative forms of data collection are referred to so that the reader can understand how the framework for interpretation of the data will intersect.

Section 2

The Empirical Study: Presentation of the women's narratives of their lives with MS

Section 2 contains the data collected and analysed in the qualitative feminist narrative study. The following 6 chapters present the data collection. The data collection contextualises the women's experiences of MS encapsulating a journey underpinned with the women's common experiences. The themes developed in chapters 5 to 10 provide an exploration of the lived experience of MS as defined by the women who participated with the sharing of their stories. Chapter 11 discusses the findings and develops further observations from the empirical study.

Specifically, chapters 5 and 6 present the women's common yet varying experiences around the beginning of their MS symptoms and eventual diagnosis of MS within the medical system. Chapter 7 examined the women's experiences and lived realities with health services and explores how these intersect with their understandings of care and support as recognised by the women. Chapter 8 presents the women's own understandings of the beginning of their MS experience. Chapter 9 portrayed some key themes developed in relation to personal relationships and the impact a diagnosis of MS has had on the women's life trajectories including employment. Chapter 10 further explored this issue moving into the women's expressions of bodily boundaries, and their coping skills, such as having a focus on hope. Chapter 11 contextualises, theorises and connects the findings held within this thesis. Furthermore, suggestions are offered and developed around women's lived experiences of MS

The themes presented in Chapter's 5 to 10 represent the lived experience of MS explored in this qualitative feminist narrative study

Theme 1: Onset of MS symptoms

Theme 2: Diagnosis of MS

Theme 3: Accessing health services

Theme 4: Making sense of MS

Theme 5: The impact of MS on personal relationships

Theme 6: Adjusting to living with MS and the body boundaries

Conclusion: Mapping out the lived experience for women with MS

Chapter 5:

The genesis of a health trajectory

Prologue

Chapter 5 represents the relationship between the women and their experiences at the onset of their MS symptoms. The women's narratives were dominated with stories of medical discourse that have had both a major influence on the women's first experiences of MS symptoms and the women's illness trajectories. A key theme advanced in Chapter 5 was around the women's feelings when they first experienced symptoms of MS. Secondly, Chapter 5 examined and contextualised the medical responses to symptoms of MS.

The narratives in Chapter 5 highlight the women's reflections of the social and emotional impact of experiencing the beginning of a chronic illness which is not easily identified. This chapter further raises questions within and around women and MS directing the reader to thought provoking insights into the onset of a chronic illness and the unparallel understandings of medical and personal discourses.

Introduction

The first part of Chapter 5 examines the women's recollections of their early MS symptoms (either the first symptoms experienced by the women or symptoms that were severe enough to attend the doctors). In the second part of Chapter 5 the women's recollections of medical attitudes to their early MS symptoms are explored. Finally Chapter 5 concludes with an in-depth analysis of Emily's story around the onset of her symptoms.

Interpretation of the data collection

This analysis chapter highlights the experiences of the women interviewed when they outlined their first MS symptoms and sought medical attention. The theme of this analysis chapter is to convey the women's experiences, (which were initially with their local General Practitioners and health centres), and represent their experiences which occurred at the beginning of their MS symptoms.

A key theme that emerged from the women's narratives was around their similar interactions with doctors at the onset of their first MS symptoms, or what they recognised as being their first serious MS symptoms. The impact emotionally and psychologically of the women's MS symptoms at the onset of MS was explored in Chapter 5. The lived experience at the onset of MS for the women is encased with feelings of uncertainty and confusion and it is these stories expressed by the women that are further explored here.

5.1 Becoming aware: Symptoms relating to the onset of MS

Each of the 16 women interviewed described the beginning of their illness as a distressing and confusing time. The women explained that they were distressed because the symptoms of MS were frightening when they first appeared. Many of the women talked about their MS symptoms as being explained away by doctors through their hormones initially. Many of the women were also dismissed by their doctors as being stressed, overly worried and suffering from anxiety.

Anxiety

The word anxiety means intense dread, apprehension, and nagging worry (Webster, 1991). The word anxious means worried and uncertain, causing worry and uncertainty (Webster, 1991). When first experiencing MS symptoms many of the women described themselves as feeling anxious, confused, apprehensive, and constantly worried about what was happening to their bodies. Some of the women described feelings of anxiety, confusion and worry in their narratives. Doris (aged 67) told me:

“I were worried love, really worried, as I had to look after the kids you know, my husband was at sea then, he was away a lot, that was normal in them days and the home was my job. I was about 20, erm yeah I would be 20 – I had 2 kids at the time but they were both under 3 years. It was my head that hurt a lot, pain round here (places hand on right side of head) and all numb. I would get sore cheeks on me face, and sore arms and me hands would ache, you know, more than they should. It was different to how I were normally. I was worried that I was having a serious problem, you know, like a stroke, or just drop down dead. That happens to people. I remember that happening to people who lived near me. Ok one day, gone the other. But the thing was it would go sometimes, then be back, then gone again. People look at you like you’re a bit mad... Sometimes I would be slurring and it must have looked like I were drinking in the day. I was always worrying but that’s me anyway”.

Doris’s narrative highlighted that when she first experienced MS symptoms it was a confusing and distressing time for her. Doris expressed the experience of MS

symptoms on her health when she says *'it were different to how I were normally'* after describing some key distressing symptoms from that period. Doris expressed the tensions she felt between looking after her family and experiencing health problems. Doris also understood some of the MS symptoms specifically in relation to her role as a wife and as a mother. For example, the fact that when she slurred her words she worried that people would think she had been drinking in the daytime which upset her as people could have misjudged her as a parent. Doris also expressed her fear that there was something seriously wrong with her *'I were worried that there were something seriously wrong with me ...or just drop down dead'*. Doris's narrative details distress and confusion at the onset of her MS symptoms. Iris (aged 71) outlined a similar story to Doris's on first experiencing MS symptoms:

"I was about 21 when I used to get sore eyes, right here (places hand on eyelids) and my vision would go blurry, hazy, like. Erm I mean that happened a lot and I was always having aches and pains, odd things that you can't say but they're just there. A bit like a funny toothache, can't describe it unless you've had it yourself. You know one of them things...I did worry a lot about em but whenever I told anyone they'd just say 'Oh Iris, it'll pass, you look fine', so you don't want to bother, so you keep on with it, looking after the kids and cleaning the home, you're looking after everybody else. And you don't have time to keep going on about it so you just try and get on with it".

Iris described her first MS symptoms as being 'odd things' similar to what Doris described earlier. Iris also explained that although she was aware that she was experiencing something different than normal with her body she didn't have the time to explore it properly. Doris and Iris both recognised that their roles as mothers and wives did not afford them the time to investigate their health. Also Iris, like Doris, explains that the symptoms were difficult to express as they changed a lot. Iris

highlighted this when she said *'and I was always having aches and pains, odd things that you can't say but they're just there'*. Iris further outlined:

“That first time, or it might have been a few times, like, that got me worried, you know, I did what you're supposed to do when not feeling right, I went to see the doctor. In them days, cause you remember I'm 71 now and that's 50 years ago, bloody hell, that's a time isn't it? Anyway, you're asking me what I did when I first got the MS symptoms, well I went to tell the doctor, and he said that it was nothing, probably too busy and all that, I was too busy, not him, he were a nice fella, and he sent me away with some pills, like a valium I think, I were to take it if I felt anxious, and that were it. I think that probably settled me at that point, as I believed it were nothing too serious and then I thought maybe it will just pass away”.

It is generally accepted that the symptoms of MS can make a person question what is happening to them as they are wide ranging and many of the sensations experienced within the body are difficult to describe (Halper & Holland, 1997; Burgess, 2002). For example, symptoms relating to sensation can be frightening to experience and difficult to express due to the nature of the feelings (Perry, 1994). Iris referred to some symptoms as feeling like a *'funny toothache'*. Josie (aged 32) also talked about a feeling of *'cottonwool over her head'* at the onset of her symptoms, and referred to the sensation of toothache as a description for some of her current painful MS symptoms. Josie explained that at the beginning of her experience with MS she found the symptoms to be difficult to describe:

“I suppose before my first big attack, you know the one that I was rushed to hospital with, the few weeks before that I had been getting daft stuff, a watery head, like drips in patches round my head, erm, tingling and a metallic taste in my mouth – I get that a lot still now, even though I had my mercury fillings changed, I used to think it was related to that, and just funny stuff that you think, did I just feel that? It makes you paranoid and you worry a lot”

Doris and Iris both recognised that their symptoms were difficult to describe to other people. Also, Doris and Iris had young families to look after so prioritising their own health needs may have been difficult for them – particularly as both of them portrayed a patriarchal picture of their lives. Similarly, Josie highlighted the difficulty in expressing symptoms that were random and sporadic.

Liz (aged 35), described her first symptoms of MS (or what she believes to be her first symptoms of MS) and how they made her feel:

“...I would have been about 17 and I was out with a group of girlfriends – we were sneaking some cigarettes and sharing a can of lager like you do. It was a cold night and I remember my toes feeling completely numb – so much so they hurt, like a throb, almost enough to make me feel sick. At first I remember thinking it must be the cigarette having an effect on me. Then, a few minutes later my hand started tingling, and it carried on through all the way up my arm. I remember saying out loud ‘something strange is happening in my feet and arms’ – my friends started laughing as I was a bit of a joker then, but when they realised I was being serious they were concerned. From that point on I never relaxed again properly because I always thought something was going to happen, well, as a young woman anyway. My friends got used to me always having odd things wrong with me. That first time though I remember really panicking, you know I got hot like I was going to faint (that was probably panic though)...”

Liz outlined the unpredictability of the symptoms of MS. Her first MS symptoms appeared out of the blue and she could not make sense of them or the effect they had on her body. Liz expressed her fear at experiencing new sensations within her body and not knowing what was happening to her. Liz suggested that the impact of these first symptoms stopped her from relaxing as a young woman. Similarly Jenna (aged 42) described her first awareness at experiencing MS symptoms and how they made her feel:

“I was training to be a nurse and I had been feeling peculiar all day. I had had trouble concentrating and just felt out of things all day as well. I got in my car to

drive to the digs I was living in at the time and I had to drive through this tunnel for a few seconds that was dark apart from the lights from moving cars. When I went into the tunnel I remember panicking because I went blind suddenly. My eyes were trying to see things, but, I just couldn't focus - I couldn't see a thing. When I came out of the tunnel I had to stop the car – I still to this day don't know how I managed it. It took me a good few minutes to get my vision back (or some of it because it wasn't clear like it should be) though it didn't return to normal. It was like there was a mesh over it, you know like a net. I felt generally lousy as well. I remember feeling cold all over and shivering. I mean I was petrified (goes very quiet and thinks for a moment). I thought maybe it was a brain tumour – I mean, you just don't know, you just don't know. It was a few years before I found out it was MS”.

Liz and Jenna described how they felt when they first experienced (what they now recognise to be) MS symptoms. Like Doris, Iris and Liz, Jenna recalled her first symptoms as making her feel frightened, anxious and confused. Barrett (1995) discussed the beginning of MS as placing the person (who is experiencing the symptoms) through a rite of passage by adjusting to a new physical and social body. Barrett's study looked at women who already had a diagnosis of MS and how they adjusted to living with their new bodies. Barrett (1995) noted the physical changes to a person's life when they experience disability and the adaptation that takes place. She concluded that both physical and social life changes are made. The women's narratives here could be signalling the start of a new rite of passage for them. Most of the women said that from the beginning of experiencing MS symptoms they thought differently about their bodies. Although the women did not know they had a chronic illness at the onset of their symptoms they identified that life was not the same once they had experienced MS symptoms. From this perspective Barrett's (1995) linking of the beginning of a rite of passage to the onset of MS symptoms is useful for exploring and understanding the women's experiences of first MS symptoms. Without exception all the women were confused and anxious when they first experienced MS symptoms and said that their first MS symptoms changed their lives.

Some of the women tried to find explanations for what they were experiencing such as Suzanne (aged 45). Suzanne outlined what happened when she first experienced MS symptoms:

“At the time we were living in Peterborough and I was working for the Mawlbry Trust, which is basically a National health trust, for mental health and learning difficulties, that kind of thing. One day I lifted a patient from the wheelchair (doing it how I was taught, you know, properly and safely) onto a buffet, but this person decided to, when they had their arms round my neck, lift their feet off the ground and basically pulled on my back. I didn’t think anything more of it and the next day I had like erm tingling in my leg. I thought it was because of the back pull that I’d had”.

Suzanne explained that she attached her first symptoms of feeling unwell to a specific event at work. Suzanne further explained:

“Anyway this didn’t get, (it was in my left leg), it didn’t get any better. It was a really weird sensation, but about two weeks previous to the back pull I had had the, I think hepatitis C Vaccination (I think it was that one, it’s the one they give to healthcare workers in case you get bitten or something), so I’d had that and I didn’t know much about links to MS or anything at that point. This went on for ages and I went to see Chiropractor erm, oestio-practor and doctor, and they would say its sciatica, or it’s this or it’s that, and one symptom was like a feeling of a wet foot, which is really, really weird, and unless you’ve had that it’s really hard to explain to someone. It’s like you’re wearing wet socks all the time it’s horrible, and I had this tingling constantly in my leg and this went on for ages”.

Suzanne further explained that because she suffers with migraine her doctor did not recognise the seriousness of the symptoms particularly as being linked to neurology or a long-term chronic illness. Suzanne said:

“You pick up the phone and you hit yourself on the head because you’ve got no peripheral vision at all. So I said to myself, I will leave it a couple of days and see, so it didn’t clear and I went to the doctor. It could be an infection he said but I’m going to give you some drops and if it doesn’t improve by tomorrow at all you must come back to me. So I went back to him and he said right I’m getting you to see the eye specialist in Bangor, Mr Agowe, and I want you up

there like tomorrow sort of thing. So I went up to see the eye specialist and he basically, did all these tests”.

Frank (1995) suggests that people need to make sense out of experiencing ill health. Using the concept of ‘restitution narrative’ Frank (1995) explains that people try and create ‘some understanding’ for what is happening to them in an attempt to restore some meaning and stability back into their lives. Suzanne’s narrative above is a good example of this as she searches for answers to understand what is happening to her body. Many of the other women offered explanations around situations at the beginning of their symptoms and this is explored further in Chapter 8.

All of the women talked about the difficulty in expressing their symptoms to other people as the sensations they felt could be very difficult to describe. As time had passed the women had found it easier to express what was happening to them in relation to MS although at the beginning of their MS symptoms describing what they were experiencing proved difficult for most of them. Guagenti-Tax et al.

(2000) found in their study of people with MS and their caregivers that the range of symptoms experienced were varied and wide, with MS being an umbrella term for a range of symptoms rather than a set criterion of symptoms. Guagenti-Tax et al.

(2000) emphasised that this was a key frustration for both people with MS and their caregivers as communication difficulties could develop. They also concluded that people with MS found it difficult to express and describe new symptoms because of the nature of how some MS symptoms presented. This is an interesting dynamic to explore as at this point in the women’s illness trajectories they did not have a diagnosis of MS so therefore had to reconcile with themselves about what

was happening to them. Additionally there is also the perspective that understanding how the body is experienced as 'normal' will be key to how symptoms are recognised as being 'abnormal'. Kleinman outlined this point (1988: 13):

To understand how symptoms and illnesses have meaning, therefore, we must first understand normative conceptions of the body in relation to the self and the world. These integral aspects of local social systems inform how we feel, how we perceive mundane bodily processes, and how we interpret these feelings and processes.

For somebody already experiencing symptoms it may be difficult to define new ones as the body is constantly in a state of transition and this would be especially difficult without a diagnosis of MS. This point is outlined by Sammy (age 30) talking about the beginning of her MS symptoms:

“...well, the early days (that I now know were MS symptoms) were horrible really cause I thought I was depressed, I was on anti-depressants, and I was obviously getting other things too, like I used to get a lot of tingling all over my body, and itchy, really itchy, and sometimes I would just cry and cry, but it was like I couldn't stop even if I wanted to. My fingers used to freeze up too, like I couldn't bend them sometimes properly.”

Sammy's narrative above details her confusion at experiencing MS symptoms yet not being able to understand them. Sammy highlighted that she had attached these symptoms to having depression yet emphasised that other symptoms confused this diagnosis for her. Referring back to Kleinman (1988) and normative understandings of the body it is important to take into account cultural understandings of the body as this will affect how the body is understood, experienced and assessed. The women experienced varied symptoms at the beginning of MS, and continued to do so before they were aware they had MS. Kleinman's (1988) understanding of how the body is experienced as normal is useful here because most of the women lived with MS

symptoms for many years not knowing they had a chronic illness. They had carried on living their lives whilst afflicted with often disabling health problems and in many cases had just adapted to their new bodies. Iris highlighted this point when she said *'you get new things, or old problems come back, you never know what's round the corner, or you don't know if you've had it before'*. Iris's comment sums up the unsettling, disturbing nature of MS symptoms.

5.2 Medical responses to the women's first MS symptoms

The women's experiences with doctors at the beginning of their MS symptoms and subsequent experiences until they were referred to a specialist for further investigation are discussed in 5.2.

The majority of the women had a negative story to tell about their experiences with medical professionals particularly at the onset of MS symptoms. The term 'medical professionals' can be identified 'as any person working in a place of healthcare, such as a surgery, hospital or day centre' (as discussed by the women). However, at the onset of symptoms stage most of the women had immediate dealings with General Practitioners (GP) or practise nurses. In the National Health Service (NHS) in the UK visiting a GP would be the first step with most ill health. A key commonality in all the women's stories was the lengthy period of time between the first visit to the doctor, a referral to a specialist and a diagnosis of MS. Many of the stories showed that doctors were the biggest gatekeepers due to their failure to recognise the women's health experiences as serious, or often offering misdiagnosis. The narratives here focus on the period between the onset of MS symptoms and a referral to see a neurologist or specialist.

Experiences with doctors at first symptoms of MS (as described and identified by the women) show that they were not taken seriously. All of the women experienced some form of anxiety when they first experienced an MS symptom(s) which is quite understandable. Most people would react emotionally to sudden illness (Frank, 1995).

Josie (aged 31) outlined a story when she felt her GP dismissed her health fears:

“I had told the doctor what my symptoms were (numbness, loss of vision, and lack of balance) and he wrote me a prescription for an ear infection. I said to him, no I don't think it's an ear infection, it something more serious, I don't feel myself and I'm worried that there is something really wrong with me. And I did I was petrified, and he said, 'here's a prescription, go home and relax' and I had to leave. I went home, and just cried my eyes out”.

Josie outlined how the doctor dismissed her serious fears about her health and patronised her by telling her to go home and relax suggesting that she appeared anxious. A few days later Josie's health was deteriorating further and she called the doctor out for a house call. When he arrived he was cross with her (it was the same doctor she had seen in the surgery). Josie recalled:

“I had got up in the morning I couldn't walk in a straight line. It was frightening. My dad was worried and he didn't know what to do with me. My mum had just died and he was grieving. By the afternoon the only way to move up and down the stairs was to shuffle on my bum, and I just knew that I wasn't right. My whole body was shutting down. The doctor came and I could tell he was mad. He asked me if I had taken the prescription for the ear infection and I said I had and he told me it takes a few days to work. He must have seen how terrible I was but he told me not to ring the surgery again that week”.

Josie's story outlined and emphasised the power of medical professionals and their knowledge juxtaposed with real life experiences and the wide gulf that sometimes presents between these two facets. Josie 'knew' that her body was not feeling like it usually does yet the doctor would not listen to her own interpretation and diagnosed

her with an ear infection. Josie's narrative here is a good example of the limited notion of rationality that medical science works within. Josie's narrative is also a good example of attempting to place subjective experiences within the parameters and knowledge base of medicine. Harding (1986) challenges the inquisition of science in her perspective of standpoint feminism and explores the limited scope of rationality which underpins medical science, and which is, by nature, bias towards women. This was the emphasis in Chapter 1 when outlining the argument of the thesis and furthermore Chapter 3 offered a discussion on some of the feminist contributions to the sociology of health and illness, specifically highlighting the social and cultural attachments placed onto women's bodies in the construction of health. The work by Martin (1989) and Wolf (2001) for example, highlighted the cultural ideologies placed on women in interactions with male doctors. When Josie called on the doctor again a few days later he was annoyed and dismissive with her to the point that he tells her to not get in touch with her doctors' surgery again that week. Smith (1988), like Harding (1986), claims that science devalues the specific subjectivities of women's experiences and within medicine this can be viewed within the practices of health. For example, the medical gaze limits and subverts the experiences that women can have in relation to their bodies because there is already a set criterion of what is valid knowledge around women and their bodies and their experiences. In relation to the women in this study the medical gaze (specifically GP in this instance) has imprinted a certain set of rules onto the women's expressions of MS symptoms. Furthermore, the women have been ignored and not taken as being credible in their reporting of their health experiences. Similarly, Emily (aged 42) outlined her fear and frustration at nobody believing her (Emily's emphasis).

“The most frightening thing was that nobody took me seriously. My body was physically changing (at the time I thought I had had a stroke or something) and the doctor told me just to relax, it made me feel worthless and to think that nobody believed me was horrible. I couldn’t use my arm properly for weeks and my shoulder was in pain and I remember thinking well if I drop down dead they will all be eating their words then” (quote taken from Emily aged 42)

Emily said she felt that she ‘*was going nuts*’ because the doctor would not accept what she was telling him about what she was experiencing. This story was reflected in most of the interviews.

Gill (aged 54) first experienced MS at the age of 23. Here Gill tells of her experiences with 2 different doctors on presenting to them with her symptoms:

“I remember as clear as day the first symptoms – the first time doesn’t leave you does it? I could cry sometimes when I think of what I might have missed, say, how different life could have been, had I been listened to at the start. Melancholic isn’t it? I know, but I wonder...my eyes gradually became hazy over a period of days, about 3. I thought it was strange and booked to see the optician. He gave me glasses for eye strain and that was that... Oh gosh it must have been about 2 weeks later when my vision went very out of sync and I had a terrible headache. I had been susceptible to migraine but this was a throb, frightening, and not letting up... My mum encouraged me to go the doctors when my arm was not working properly – I couldn’t lift it up and it was very heavy. I had been up for about 3 nights at this point with my sore head and arm and was shattered. The doctor said it could have been migraine and told me to rest at home for a week or so and go back if not letting up. I left it 10 days and by this point I had gone numb as well in my arm and the top of my leg. This time I saw a different doctor. He asked me about my periods and if they were regular, that kind of thing, erm contraception and checked to make sure I wasn’t pregnant. He then prescribed me these anti-depressants which confused me because I didn’t feel depressed but he was the doctor and because I had been worried about my head and arm I thought well I am down at the moment. He said depression can cause physical symptoms and that these should sort out my problems...I took them for 10 years”.

This dismissal by doctors of women’s health experiences is not a new phenomenon.

What Gill and the other women’s narratives describe are the medical and cultural inscriptions which are placed onto female bodies (Grosz 1994). When the doctors

respond to the women by checking period cycles or offering anti-depressants to calm them down the behaviour of the doctors can be viewed as a reflection of the patriarchal practices deeply embedded in medical discourse (Ussher, 1997). It is possible to link medical knowledge to the wider structural relations of wider society. For example, early medical discourse in the 19th century relates to the social and economic system of industrial society (Nettleton, 1995). Medical literature shows that the body reflected the society at the time of factories and communication systems with certain parts having specific functions (Nettleton, 1995). Nettleton (1995: 122) outlined that:

in the 20th century molecular biology drew on metaphors from management and information science, the coordinating centre of which is the central nervous system (Nettleton, 1995; 2006).

Martin (1989) emphasised this point in her study of the 'Woman in the Body'. Martin (1989) outlined that the female reproductive system is described discursively as being dormant and culturally placing women's reproductive capacities into a passive and inactive framework. One of Martin's (1989) key findings in her study was that the women's descriptions and understandings of their own bodies reflected that of medical discourse. Drawing on medical literature from around 1970 Martin (1989) articulated that the female reproductive system is outlined in medical discourse as a system of hierarchy interacting within a process of orders and directions. This same process is culturally applied to women's bodies in other hormone associated conditions and it is viewed within this theme of a breakdown in the system of authority (Nettleton, 1995). More recently, Lury (2005) recognised the role that hormones play in the signal system of thyroid problems, and similarly (2007)

recognised the role of T-cells in people diagnosed with AIDS. The emphasis here is the cultural and social implications in the production of medical knowledge.

Significantly, all the participants in this study of women with MS had experienced questions relating to their reproductive cycle. Martin (1989) outlined that the women in her study (Ibid 1989) accepted menstruation, hormone cycles and other related female bodily practices as being part of life, drawing on their own personal experiences as well as accepting these 'truths' from the medical model. These findings from Martin's study were echoed in the interviews conducted in this empirical study. Many of the women accepted that hormones and childbirth temporarily created a breakdown for women's bodies although this was juxtaposed with their own understandings of their own bodies. Iris's narrative reveals a GP visit early on with her MS symptoms:

"Yes I did,(referring to visit to the GP after experiencing numbness) and at that time, you can't believe this really, it's almost unbelievable, he checked me, like a feel round where I said it were numb, lifted me arms and all that, then he said to me, 'Iris, I can't find any evidence for a stroke', as when I went in, I'd obviously said to him, I'm worried I've had a stroke, and he said 'I think you should go home and take a rest for a few days, and I think you'll find your arm will feel better, you seem uptight, something like that he said anyway, can you believe that?'"

Another of Iris's narratives reveals that when she had had one of her children, her symptoms became mixed up with explanations of hormones. Iris said:

"Well, it were after I had, I think it were Peter, when I felt terrible, with pains and sore muscles, and this were when my vision was starting to go wonky as well. I would still be in me twenties then, probably about 24, and I were breastfeeding too, so he must have been under 1, and I just couldn't shift the odd things, you know. This one day, I remember limping about the house, you see, me legs were sore, but I couldn't walk straight, it were me eyes, but me whole head was funny, you know that, and then I tripped up, and I thought bloody hell, I could've had the baby in me arms then, and then it would have

been a disaster. So, I asked the doctor about it, you know, what was happening to me, and how I'd had these odd things, and that I'd had some pills but they didn't work (**reference to being prescribed anti-depressants**). He said, well he explained to me really, that having babies takes time to recover from, that me hormones would settle down and that, he give me Valium then I think, I didn't take em though, I was frightened of that stuff, but he tried to help me out, you know..."

Challenges

One common theme of all the women's stories was the way that they had been treated when they first presented with MS symptoms at their GPs. The women had all experienced some degree of questioning that specifically related to being a woman. For example, there were many questions around their reproductive cycles, around anxiety related behaviours and feelings of depression (with these questions being linked in with the disruption of hormones at some level) when they had presented with their MS symptoms to their GP. Sammy said that her doctor asked her about depression and anxiety and offered anti-depressants when she visited him with numbness and pain in various parts of her body. She said he refused to take her concerns seriously and it took several visits before her symptoms were discussed further.

However, these first experiences with doctors and other health workers varied in degree of severity and some of the women approached them differently and more directly. Also, some of the younger women felt that the immediate links to hormone conditions and anxiety, particularly without any other suggestions, were inappropriate by medical professionals. For example one of the younger women Jesse (aged 26) said:

"I strongly oppose the idea that doctors throw anti-depressants at women with MS. Whatever my beliefs into what and how the disease originates I get very

cross that these zombie drugs are offered about. I do tell the doctor though so he knows my view and I must say he does respect it. It's very important to take a stand on these issues, it really is". (Jesse aged 26)

Jesse's narrative above reflected the opinions of some of the other women, particularly the younger women. Many of the women's attitudes of challenging medicine had occurred over time and were based on their experiences. The experience of being ignored in a medical context had taught some of the women that you need to be firm and know the system so you were able to challenge doctors. Josie reflected on this:

"I think that you learn through what your experiences have been, and what other people tell you. Now I always write a list when I'm going to the doctors and I make sure I stick to it. I always know what I want to get and generally I am good at sticking to my view now".

Josie had learnt to become proactive over time and she said she had not been naturally challenging towards medicine until her own experiences. Contrasting with this Jesse revealed that when she first experienced her MS symptoms she was quite persistent with the GP about the severity of her experience. She would not let her symptoms be passed off as something less serious such as migraine. For example, like Jesse, Louise said:

"I know that doctors can be extremely gendered in their approach to healthcare for women but as a young woman training to be a nurse I know that I am more than capable of challenging the traditional models that dominate some medical perceptions. I also know that MS is a puzzle to most medical doctors and that is why I choose to explore alternative routes to take care of myself. Even when I first started with symptoms I wouldn't accept that it was linked to my periods".

Some of the younger women appeared to be more assertive overall in their approach to healthcare but this had been developed through their own experiences. Also,

another possible explanation is because many of the younger women were educated and had the skills to search for information and apply it.

Misdiagnosis

Most of the women interviewed had been told they had anxiety problems and their symptoms had also been linked to imbalances with their hormones (particularly the women who had children). Doreen outlined:

“After having Maureen I felt weak and tired a lot. This carried on for, erm, let me think, erm she must have been 3 before I started to feel like I did before having her...I had felt exhausted, more than tired, totally shattered, my muscles would ache, erm, hurt a lot and my eyesight was terrible for a while, blurred with a sore head, sore skin too in different places. And sometimes my cheeks might be sore then the pain would move to my arm, or top of my leg, it’s a funny thing and it takes a while to get your head round it. I remember going to the doctors with some of these things, like if they got too bad, or worried me, but he would just say not to worry and didn’t seem concerned. When I had first gone, it was with the vision and soreness on my head, and I had a very sore leg, weak and crampy, it was keeping me awake at night, Maureen would not be 1 yet, and he said it was my body settling down after having Maureen. I thought it was normal then, you see, although none of my sisters or neighbours had these things after having their kids I just accepted that, cause you do with doctors”
(Doreen aged 69)

All of the women interviewed had experienced MS symptoms at a young age, several being teenagers. Most of the older women could trace their first symptoms back to their early twenties and each was over the age of 40 before MS was confirmed (further discussion on this in chapter 6). They had spent many years battling with the symptoms of MS, usually explained as a hormonal, depression or anxiety problems.

Iris (aged 71) details this below:

“I went to the doctors for a lot of years, a lot of years before I was looked at properly. Doctors said it was me hormones and that, so you just take what they give you at first and you don’t question. Why would I? In my day women didn’t question (not like they do now, it’s different now), and the thing is you do have ups and downs with your periods especially when you’ve had babies. I thought

that the things I were getting happened when you'd had a baby, I mean I were young and didn't know any better". (Iris aged 71).

Iris explained that she had accepted the doctor's diagnosis of hormone problems due to her young age when she started having MS symptoms. Iris also outlined that she believed that pregnancy and childbirth could leave a woman with hormonal problems so accepted this could be causing the symptoms she was experiencing. This lack of questioning was a common theme among a lot of the women and they had accepted their doctor's diagnosis. Iris also felt afraid and outlines an experience with her doctor around her early MS symptoms:

"What you have to remember is I knew the doctor, at that time, since I were a kid, he knew the family, me mum, and sisters, so you don't want to make a show of yourself, and I'd been going a few times, with the sore eyes, funny vision, the odd pain here there everywhere, you know MS, no sense or reason to it, and this was probably like the 3 or 4th time I'd been about this, say over 6 months or so, and he just looked at me, and then he said, well Iris, we have talked about these symptoms before and I did prescribe some pills (he said the name you know I can't remember) and I think it is down to anxiety – are you coping ok with the family, and the children, you know that kind of thing, well hell, he put the fear in me, he did, as I didn't want people thinking I couldn't look after the kids, I think I probably had 1 or 2 at this point".

Iris expressed the fear she felt when her doctor questioned her about if she was coping with her family life after visiting him 3 or 4 times about her symptoms. Iris noted '*he put the fear in me, he did, as I didn't want people thinking I couldn't look after the kids*'. Iris' example also highlighted how medicine draws on the pathologisation of women's bodies to dismiss their subjective experiences, often giving women a limited scope to discuss their subjective experiences. Ortner (1974) recognised that (universally) women's reproductive roles have become devalued and pushed into the private sphere. Ortner (1974) further asserted that the association of gender and nature

has generated a specific female personality (for example attaching specific realities to certain female events such as pregnancy and childbirth). This already embedded stereotype of femininity intersected with symptoms of MS had placed the women in a confused and invisible space to articulate their symptoms of MS clearly. For example, many of the women described experiencing symptoms after each child they gave birth to which again was defined as hormonal problems without further investigation. Doris explained this below:

“With each child I was always ill afterwards. Not when I was pregnant, usually I was alright for nine months, but afterwards I always had the flu or something - my daughter who is a nurse now said she had read in a book that this happens to women with MS. When they’ve had a baby they can get an attack of the MS because their bodies are tired with all the feeding and looking after. What do you think about that? They always blame women’s hormones don’t they?”

There is also a growing body of research around MS and pregnancy that supports the view that hormone imbalance can be associated to the progression of MS (Perry 1994). However, this information is currently presented with supportive measures, such as healthy eating and vitamin intake, for women with MS who are deciding to have children (Perry, 1994; Halper, 2001). In relation to Doris’s comment, research has shown that when women with MS are pregnant their health can improve with some women becoming symptom free throughout their pregnancies, but may decline after the birth (Burgess, 2002). Doris displayed a tension between her own experiential knowledge and the embedded gender stereotype around women, pregnancy and childbirth. For example, Doris recognised that doctors had dismissed her experiences by associating hormonal imbalances as to why she was feeling unwell. This had occurred over many years and Doris found it difficult to now adjust to knowledge that may be helpful for women living with MS. Some of the older women had been encouraged by their doctors not to have any more children once their

symptoms developed, although the women were only told they had hormonal problems, depression and anxiety problems. Their doctors may have suspected MS was the cause of their symptoms, but whatever the cause, the women were not being given any information to make informed choices about their bodies. A study conducted in Germany by Koopman and Schweitzer (1999) outlined that people with MS wanted more structured information about their diagnosis and the procedures that had occurred. Koopman et al. (1999) found that out of 126 respondents, over 2/3 of them had wanted to receive a diagnosis of MS as soon as possible from when their symptoms had started and did not want to go through a process of repeated visits to doctors with MS symptoms for a period of time prior to a diagnosis. They also found that people with MS wanted as much critical information about MS and its progression as possible.

Another common theme was the diagnosis of depression and anxiety to explain the women's symptoms. All of the women had experienced this but some of the women, such as Jesse and Josie, had actually challenged their doctors and insisted on further investigation (however this did not mean that they received further investigations). However, it tended to be the younger women who were more challenging. Many of the women had accepted this inscription of depression as they did not feel comfortable to challenge the doctor. An example of this is

Doreen's narrative below:

“I was put on tranquillisers years ago...too many to remember. The doctor just said I had anxiety and depression and he said the tranquilisers would relax me. I must admit, they stopped making me worry about the symptoms but it's not right is it to be spaced out for all them years? I do think I missed out on a lot with the kids because of this”.

Many of the women had had a period where they had been placed on tranquillisers or anti-depressants for the symptoms they were experiencing. Some had been on strong medication for a period of 20 years, with some of them coming off it when they received an official diagnosis of MS. Emily (aged 42) said that she was given anti-depressants. Emily could also not decide as to whether she was depressed or it was just a part of who she was. She said she had experienced cycles of 'down periods' for such a long time that she was unsure if they were related to MS or just her personality. For example, this is what Emily said about depression and MS:

“...some days I get very down. Very very down and I just stay put till I can rise out of it. Depression. That's what it is. I don't know if it's part of the MS, or if it's because I have a lot to be pissed off about”.

This confusion of how the women felt about their experiences was common.

5.3 Understanding the responses

All 16 of the women interviewed said that they were offered anti-depressants for their initial symptoms when they visited the doctor for advice. Sometimes the anti-depressants had been offered on a second or third visit for the first symptoms.

Also as the symptoms of MS can initially appear sporadic and inconsistent this then enhances the distress and confusion for the person who is experiencing the symptoms (MS Society 2006). MS is a disease of the central nervous system and is an umbrella term for a wide range of symptoms (Sibley, 1988). There are no set symptoms just similarities between people's experiences. The most common symptoms are fatigue, visual problems, pain, stiffness and spasms, depression, cognitive problems, speech problems, continence issues and sexual problems (Perry, 1994). It is predominantly

experienced by women with a current ratio of 4:1 (MS Society UK, 2009). Currently there is no known cure for MS and no generally agreed definition of the origins of disease (Halper & Holland, 1997; Burgess, 2002). These components added together make the beginning of MS frightening for those – and those close to them – experiencing it.

All of the women outlined a distressing story when they had presented their MS symptoms to their local doctors. These stories encapsulated a feeling that the first symptoms of MS rarely get recognised on first reporting with many people having to represent the symptoms several times before being taken seriously. In 1995 a study by Haberfellern & Markut showed that the average wait between first symptoms of MS and diagnosis was 5.6 years. They suggested that their study revealed that most patients require frankness about their health and this was neglected in their diagnosis and previous symptoms for a relatively long period. This was echoed in many of the women's stories. All of the 16 women suggested that doctors did not take them seriously when they presented with symptoms of MS. All of the women had multiple visits to their doctors over a period of months and years before they were referred to a specialist, and even then faced many more visits to hospital before a diagnosis of MS was confirmed.

At the onset of their symptoms the younger women who were interviewed said they felt frightened and this had caused them to seek help immediately. The women had identified that because the initial symptoms caused them distress and were overwhelming and could be frightening they visited the doctor quite early on in their experiences of symptoms. Most of the younger women suggested that earlier

recognition that something was wrong with their health, rather than experiencing self-doubt about what they were feeling, could generally urge earlier visits to the doctor and lead to a quicker diagnosis of MS (however Josie's story did not reflect this). However, in terms of other illness and specialist treatment there was still a significant period between first symptom and diagnosis (Aronson et al. 1997; Halper and Holland, 2002).

5.4 Impact of MS symptoms and no diagnosis

These first experiences of MS placed a disruption on these women's life trajectories. A description of uncertainty was emphasised by all the women who were interviewed. For many of the women this was highlighted as a frightening and negative attribute of MS particularly prior to diagnosis. This was because it added to the confusion of the situation. Not only did the women have to attempt to adjust to their changing physicality's but they could not offer an explanation for what was happening. Initially this affected the women in their immediate social interactions because friends, family and colleagues would question them about what was wrong with them. The effects of their symptoms were noticed straight away and the women explained the various responses they received. Jenna (aged 42) was working full-time at the start of her more serious symptoms and although she had confided in her husband about what was happening she chose not to tell her workplace. Jenna, was managing a hospital ward at the time when her most serious symptoms started and she was being seen by a specialist, told an all too common story amongst the other women about the early days of her MS symptoms prior to diagnosis:

“I was managing a (hospital) ward and I didn't want to disclose what was happening with my health – I mean I wasn't too sure what was happening myself and I know that employers can get nervous around health problems and I

had just been promoted so I decided not to discuss it. This made me feel vulnerable at work as I had to be careful lifting patients in and out of bed, and make sure I wasn't putting them at risk as well as myself. It sounds daft now, saying that and being surrounded by doctors, but I must have just not trusted them”.

The concept of uncertainty affected the women in both their public and private lives. Several of the women commented that experiencing the physical symptoms of MS yet not having a name to place it or understand it undermined their confidence. As Suzanne highlighted when discussing the beginning of her MS symptoms and prior to her diagnosis:

“It affects everything you do from going to the shops to trying to carry out your job. I didn't want to keep discussing it with my husband because I felt stupid because the doctor was telling me I was fine. I started questioning my ability to make decisions and looking back it was because of the MS, and the dismissal of my symptoms... It's outrageous and does make me angry now, yes it does.”

Suzanne highlighted the impact of experiencing MS symptoms without any medical recognition for what was happening to her body. Suzanne explained that she experienced self doubt questioning her own ability to make decisions. Suzanne linked this to her experiences of living with MS yet not having a medical recognition for her symptoms. Similarly Gill (aged 54) outlined:

“I spent a good 15 years struggling with the idea that I was experiencing these body dysfunctions, bad episodes and things, because of depression. It takes it out of you, it really takes it out of you. I thought that I was experiencing one thing yet it turns out I had been living with MS yet I didn't know it. If only I had been told when I was 23 by the doctors. My life could have been different as I could have accepted the disease and learned to live with it. I manage now having relapsing remitting...but I know about MS now, I have information to read and make decisions...I didn't have that before”

Gill's narrative outlined the tension between being informed that she had depression to later being diagnosed with MS. Gill had experienced this over a period of 15 years

and had related her physical decline to having depression. Gill suggested that this impacted on her ability to accept she had MS.

After a diagnosis of MS the concept of uncertainty was rooted within the progression of MS (this is discussed further in Chapters 6 and 7). For example, several of the women commented that MS brings a different day – each day. However, after a diagnosis of MS many of the women struggled to come to terms with living with a disease yet not knowing what it was. Emily (aged 42) said:

“Of course I never know what’s happening with my body each day. The MS makes everything unpredictable and some days I get really depressed. It can hurt to be tired, that kind of tiredness that you get with MS and it just grabs you and you can’t do anything with it but get in bed. That unpredictability gets me but I manage it much better now...it help so much when you know what it is, I know I have MS now so I can do something with that”.

In any case of ill health a feeling of uncertainty would be for many people a natural response to experiencing changes physically and emotionally. Understanding and information can prove to be essential tools when dealing with such incidents as echoed by the women who were interviewed. For many of the women the period between the onset of symptoms and receiving a diagnosis of MS was a lengthy one. Thus many of the women spent years trying to understand what was wrong with them and juggling to cope with their own lives and responsibilities at the same time. These women described years of anguish and emotional pain that could not be articulated in any clear way. These women experienced a lot of frustration at the hands of the medical regimes and were diagnosed with depression and anxiety by their doctors many times before their symptoms were investigated.

Illustrative study – Emily’s story

Emily’s story about the onset of her symptoms describes medical gendered discourse used by doctors at the beginning of experiencing serious MS symptoms.

“About 10 years ago, it was a Sunday and we were stood outside, and I said ooh I have this tingling sensation in my back. I didn’t know what it was but I’d been to see my great grandma who had shingles so I rang the doctor and said I have this tingling in my back, been to see my grandma who has shingles, can I catch it – he said ‘oh yes it sounds like shingles, go home take paracetamol’, you know that kind of thing. The next morning when I woke up I thought I’d had a stroke, and I could feel these tingles moving up and down my spine and back and I could track where they were going. I was frightened. The next morning when I woke up I couldn’t move my left side, there was weakness, (it was) I just thought I’d had a stroke, it was so scary. I rang the doctor, then went to see the doctor, and erm, this was a few days later because I was unsure what to do and I thought it was probably not a stroke as I was still here. I went to see the doctor a couple of days later, yes that’s right, and as doctors do he said I was overweight, depressed and I had too much time on my hands. That was it; he said ‘the trouble with young women nowadays is they have too much time to think’. He gave me some Prozac”.

On first reading this narrative (a naïve interpretation) it is clear to see that Emily is aware that something is happening to her when she has ‘tingling in my back’ and she attempts to link it to a recent illness of shingles in the family. Emily is attempting to make sense of what is happening to her and her narrative reflects the tensions she feels about what is happening to her. Martin (1989), Frank (1995) and Barrett (1995) explore the concept of understanding and making sense of what is happening when the body experiences something new. The deep structures of the narrative identified 2 key plots of the story. There is one where Emily displays here fearfulness when she recalls her first serious symptoms as ‘when I woke up I thought I’d had a stroke, and I could feel these tingles moving up and down my spine and back...’ Emily described her distress at these symptoms saying she was ‘frightened’ by what was happening to her. The second plot of the story can be seen when Emily says that the doctor told her she was ‘overweight, depressed and had too much time on her hands’. She quotes him

as saying ‘the trouble with young women nowadays is they have too much time to think’ – he then prescribed her the anti-depressant drug Prozac. Linking in with perspectives which examine the view of ‘biopower’ (term identified by Foucault, 1987) the doctors’ response to Emily that he drew on the cultural aspects of her feminine identity to solve her health concerns. As highlighted in Chapter 3 the social-medical construction of women’s bodies can be used here to explore Emily’s narrative.

Prior to these severe symptoms that Emily was experiencing she recalled that for many years beforehand – she estimates about her late teens – she had been visiting the doctor on and off for numerous health problems. Here Emily outlined:

“I’d took my dad with me as I’d been going to the doctors on and off for years with various things such as depression or this funny thing, or that strange feeling, and I’d got to the stage where I just thought everybody thought I was mad. So I’d took my dad and came out to the waiting room. (sorry I’m going to swear now) and I said too him ‘well that was a fucking waste of time as he thinks I’m mental’. All I came away with was a Prozac prescription. I went back to my mums, you know, absolutely distraught, didn’t know what was occurring, carried on, I did go back and see another doctor, who referred me to a neurologist, but this was all about six months later. In the meantime this numbness and walking and holding my arm like I’d had a stroke lasted for about 3 months”.

Emily expresses her frustration and pain at being unable to gain acknowledgment from the doctor about her symptoms. The plot of Emily’s narrative suggests that she is making links between many visits to the doctor over a period of years when she said:

“I’d took my dad with me as I’d been going to the doctors on and off for years with various things such as depression or this funny thing, or that strange feeling, and I’d got to the stage where I just thought everybody thought I was mad”.

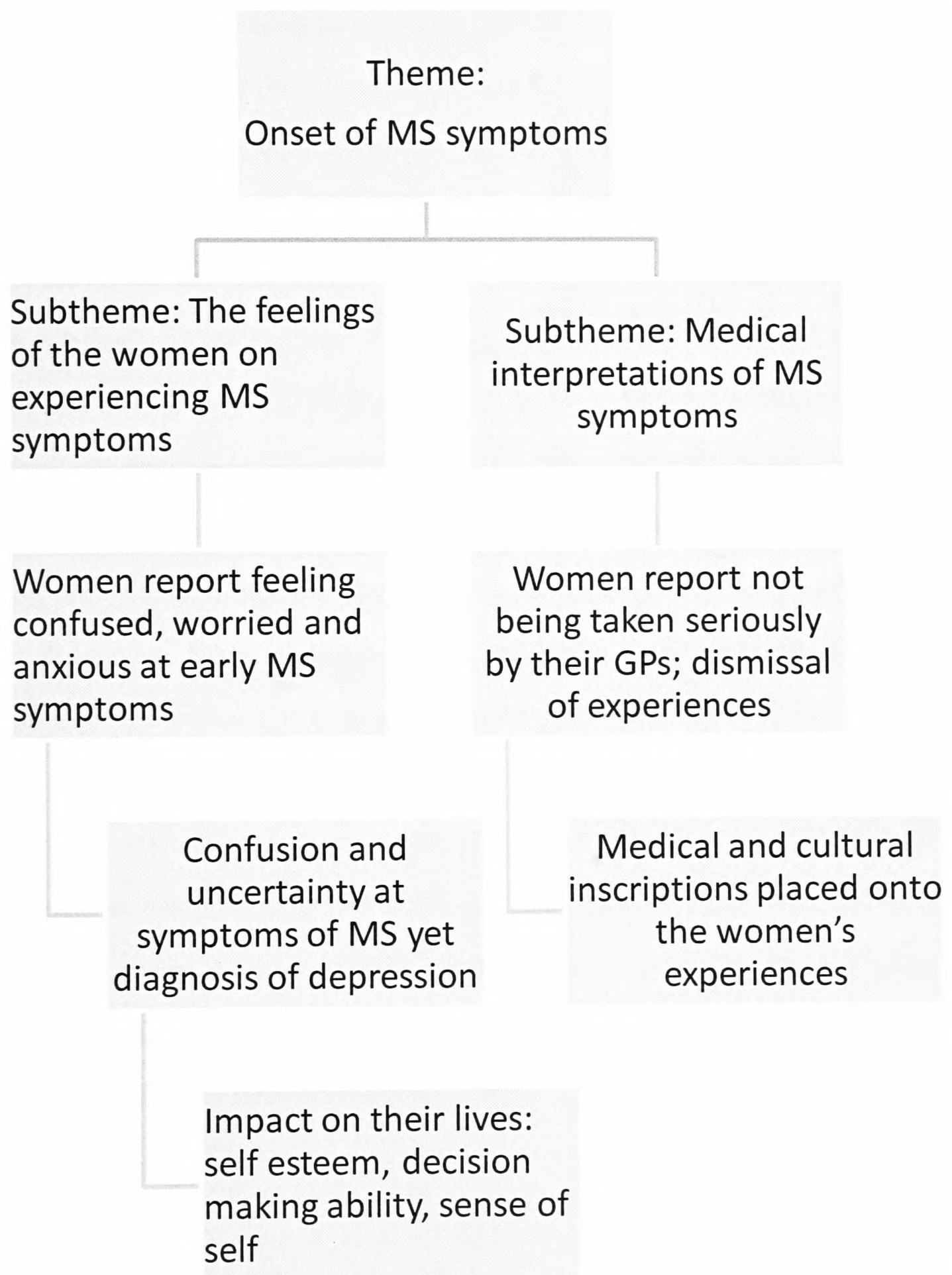
Emily remarked several times in her narrative that doctors, and people, must think she is 'mad' or 'mental'. Emily further explained:

Went back to the doctors and I said you're supposed to have jived up this MRI, and I found out they hadn't done anything. They hadn't jived it up at all. They hadn't done anything. So this time I insisted on the letter being sent etcetc, so I got the letter confirmation sent saying that they were waiting for a quick appointment. Anyway a few more days went by and my face became very painful, very tingly and very painful. I was back at the doctors, and they were telling me the obvious, 'you need to lose weight', and 'are you taking your Prozac?' so I was really pissed off with the doctors by this point. But anyway I went one day with my mum because I thought a bit more support and they may not tell me I'm overweight, you know if my mums there. So I went to see this doctor and I said to him look my head feels like its been chopped in half, filled with concrete, and it's all tingly, and I'm frightened to death, I don't know what's happening. I said to him I don't know if I've got a tumour growing in my head, I don't know what it is. By this time we had already gone through all this the doctor turned round to me and said 'what you're describing sounds like stress. I suggest you go home, forget about it, and you try and de-stress'. With which I just picked my bag up and walked out.

Emily's narrative could be viewed as expressing her annoyance and discomfort at not being taken seriously – although disturbingly Emily's narrative reflects many of the other women's narratives in this study. Emily's narrative is a good example of how the power of sexist medical discourse is played out in consultations – or another way of understanding the experience would be as a representation of 'biopower' (McNay, 1994).

The onset of MS

Figure 5A presents the theme and subthemes that form chapter 5, exploring the experiences of the women at the beginning of their MS symptoms



Summary

Chapter 5 looked at the relationship between the power of medicine and the impact that medical discourse can have on women's experiences – in this case women with MS. Chapter 5 outlined the first experiences of MS for some of the women and how it had made them feel and the consequent disruption it placed on their lives. Secondly, the discussion explored what happened when the women had presented with their initial symptoms at their local medical houses (GP surgeries). The women's narratives have shown that they were often treated unfairly by GPs with implications for their psychological and physical well being. Significantly all of the women had been dismissed by their doctors at the onset of their symptoms and many of them had been offered anti-depressants as a resolution. This chapter has also highlighted a plethora of misdiagnosis – and this will be discussed further in chapter 11. Also the impact on the women's sense of self was discussed looking at some of the women's thoughts and feelings on being misdiagnosed for a number of years. Chapter 5 further highlighted that doctors proved to be the biggest gatekeepers for the women as they needed to refer them to the hospital for further tests. The women each experienced a wide range of symptoms at onset yet they all received a similar format of questioning that was specifically linked to their bodies as women. This was a significant finding in relation to women, MS and medicine. As the women ranged in age over a 60 year period the study showed that therefore the research identified a patriarchal inscription of women's bodies in medical discourse.

Chapter 6: The journey to a diagnosis of MS

Prologue

In Chapter 5 the process of visiting doctors with symptoms of MS proved to be a distressing and harrowing experience for the women due to the responses by doctors to the presentation of MS symptoms, and for most of the women many years of misdiagnosis occurred. Chapter 5 highlighted that the misdiagnosis of MS symptoms was the biggest gatekeeper to getting a referral to a specialist at the hospital. Chapter 6 presents the women's experiences of reaching a diagnosis of MS. All the women interviewed had received a diagnosis of MS although this was not an easy process for the majority of the women. However, when a referral had occurred the women faced another battle to receive a diagnosis of MS. The wait between seeing a neurologist or specialist at the hospital to receiving a diagnosis of MS was traumatic for many of the women. They expressed key concerns around the length of time between appointments; the conducting and the receiving of test results; and the aftercare provided. In some cases the women had not had the test results explained properly to them and had been given little information about what was happening to them. This chapter furthers a discussion of women's medicalised bodies and explore the process of diagnosing MS.

Introduction

Firstly, the clinical diagnostic procedures for MS are outlined. Secondly the theme of ‘diagnosis’ is presented by examining the women’s experiences with timescales; tests and result procedures and their emotional responses to their diagnosis of MS.

Interpretation of data collection

The theme of a diagnosis has been organised for discussion drawing on the diagram below. Specifically, the time the women waited for a diagnosis if MS is discussed; the procedure of tests and results as reflected by the women and then a discussion about their emotional responses within the processes discussed.

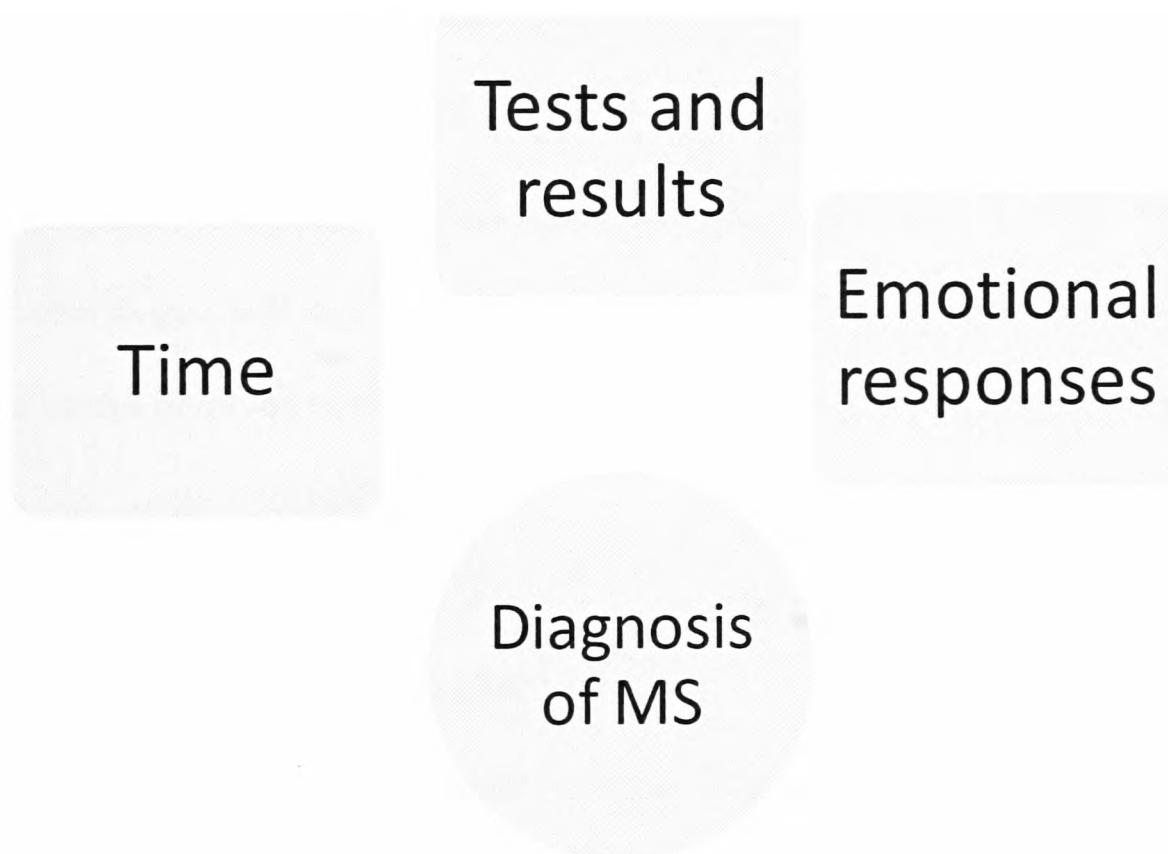


Diagram 6A highlights the theme of ‘diagnosis’.

6.1 Current medical diagnostic tests for MS

The following are the health routine tests and procedures currently used in suspected MS (and sometimes for other suspected neurological conditions). These take place once a person has been referred to a neurologist or specialist usually from the doctor's surgery. However it is important to note that these tests will vary depending on where they are taking place – for example a specialist unit such as The Walton Centre Liverpool, may have access to more specialists in the area of MS specifically. This would therefore impact on the reading and qualification of test results received.

Neurological examination and history

A neurologist conducts a history of a suspected person with MS. The neurologist asks lots of questions about past symptoms and problems, which may help to explain current symptoms (Burgess, 2002). As outlined in the MS Society Booklet 'What is MS' the neurologist will do a physical examination to check for abnormalities in nerve pathways involved in movement, reflexes or sensation (MS Society Booklet 'What is MS', page 4, 2012).

Magnetic Resonance Imaging (MRI)

The MRI scanner uses strong magnetic fields to create a detailed image of the brain and spinal cord (MS Society booklet 'What is MS' 2012). It is a very accurate examination and can locate the exact size of myelin damage (Burgess, 2002). The MRI procedure is carried out in a full body scanner and the process takes approximately 30 minutes and is painless. MRI scans confirm the diagnosis in over 90 % of people with MS (Burgess, 2002; MS Society booklet 'What is MS', 2012).

Evoked potentials

This involves testing the time it takes the brain to receive messages. Small electrodes are placed on the head to monitor how brain waves respond to what is seen or heard (Halper, 2002). If myelin damage has occurred, messages and responses will be slower (Perry 1994).

Lumbar puncture

A lumbar puncture is conducted under local anaesthetic as the procedure involves a needle being inserted into the spinal cord. A small sample of the fluid that flows around the brain and spinal cord is taken and tested for abnormalities (Halper et al. 2010). The aim of this procedure is to test for antibodies in this fluid as this is common in people who have MS (showing that the immune system has been at work in the central nervous system) (Burgess, 2002).

Other tests

To rule out conditions that mimic MS, other tests may also be carried out such as blood tests and inner ear tests to check balance (Burgess, 2002).

6.2 Time: symptoms to diagnosis

For most of the women there was a significant period of time from the onset of their MS symptoms to receiving a diagnosis of MS. Chapter 5 discussed the women's initial experiences with their local doctors and outlined the lack of understanding about MS symptoms and the misdiagnosis that had occurred. For most of the women this happened for a number of years.

All of the women interviewed had received a diagnosis of MS from a neurologist or specialist after having some or numerous tests conducted as outlined in section 6.1. Table 6A displays the length of time that incurred from the onset of MS symptoms (as identified by the women themselves) until an official diagnosis was given. (The table presents the women in ascending order of age).

Table 6.1 displays the length of time in years from the onset of MS symptoms to a diagnosis of MS.

Name	Time from first symptoms of MS to diagnosis of MS
Louise (aged 21)	3 – 4 months
Jesse (aged 26)	2 years
Sammy(aged 30)	8 years
Josie (aged 32)	7 years
Liz (aged 35)	14 years
Alison (aged 39)	10 years
Jenna (aged 42)	13 years
Emily (aged 42)	10 years
Suzanne (aged 45)	12 years
Rebecca (aged 46)	3 months
Gill (aged 54)	25 years
Linda (aged 57)	3 – 6 months
Alice (aged 67)	29 years
Doris (aged 67)	20 years
Doreen (aged 69)	27 years
Iris (aged 71)	25 years

Table 6.1 outlines the time period from the women’s onset of MS symptoms to receiving a medical diagnosis of MS. The women’s timescales had ranged from 3 months to 27 years. As you can see from Table 6.1 the bulk of the women interviewed

had waited at least 7 years and up to 27 years, with just 2 of the women obtaining a diagnosis within 3-4 months, and Jesse waiting 2 years for a diagnosis of MS.

Sammy (aged 30) had spent 8 years of living with MS symptoms before a diagnosis of MS was given. Like many of the women in this study Sammy suggested that she had seen different neurologists on different visits to the hospital and had been given conflicting diagnoses at times. This was a common story with many of the women in the study. There was also a lack of consistency, at times, with neurologists or specialists in the area of MS and this could be seen to impinge on the information that the women received about their health. In several cases no information was provided. For many of the women this lack of consistency was a key problem and impacted on their physical and emotional well-being. Sammy (aged 30) conveyed a situation that outlined this point:

“...I saw this one neurologist at the hospital who told me on my second visit – after I had had the MRI – that I probably had inflammation of my brain. Before this I was told the MRI would be looking for changes on the brain, some clinical things that indicate MS (by another neurologist I saw that day), but I was confused at this point ‘cause, I was like, ‘what’s inflammation of the brain? I had never heard of that and it sounds terrible, telling someone quite matter of factly that their brain is inflamed (laughs at the situation)...I remember asking about medications or treatments for these problems but I was just told to wait and see what the results said. But that’s difficult when you never get told the results by anybody. Who do you ask? It’s always a different doctor you see”.

Sammy recognised her frustration at not having a clear and concise conversation with the same neurologist about the tests being conducted. Josie also outlined an experience that occurred whilst at the hospital similar to Sammy’s. Josie had waited 7 years from her first emergency rush to hospital until she received a diagnosis of MS. Josie had already worked out that she probably had MS long before her official

diagnosis and said that she was only eventually given this information (that she had MS) when she pushed the neurologist for a diagnosis of what was medically wrong with her (Josie's emphasis). Josie said:

“When I was first rushed to the hospital, when I literally collapsed at home, they told my dad that I had inflammation of the brain...I was told this on and off for the next 7 years, it was a nightmare, as I was never really told properly what that means. You know, I pushed for explanations but when you're ill and poorly as well it's difficult, you know...I would go to the neurologists every 3-6 months telling them about new symptoms and I once asked out right if it was MS and they managed not to answer...I took my dad with me for one appointment and I had written a list of questions and it was at this appointment they confirmed I had MS”.

Josie, like Sammy, had felt confused by the explanations given by different neurologists. Inflammation of/on the brain is a clinical term that describes neurological activity in people (Burgess, 2002) with MS yet this was never outlined to either Sammy or Josie. This was a commonality within all the women's narratives with many of the women left feeling confused about medical terminology. Many of the women also felt that there was not enough information offered to them about MS especially when they received their diagnoses. During this period of accessing hospital care for further tests, Sammy and Josie said they had been given little information from the neurologists they had contact with about what was happening to them.

Josie said that nobody explained anything to her about what was happening with her body or what drugs she was being given. In fact, Josie said that when she was being tested nobody gave her any insight into what she was being tested for. Josie said:

“...when my tests were being carried out I was really poorly, and was out of it. I was ill for such a long time (it was my first relapse and I didn't know it was going to go away) and I didn't know what was going on. Nobody explained

anything to me and they left me to recover, which was slow, very slow actually, and I just kept my appointments every 3-6 months. I used to try and ask about what they thought was wrong with me but nobody ever gave me a clear answer. And at that time I was weak and tired...my mum had not long been dead...this added to the lack of questions i think because the family were grieving, so although they were really worried about me, they weren't focused about it, you know, because of my mum".

Josie's narrative revealed that she had 2 key life events happening to her when the medical tests for MS were being conducted. Firstly, she was experiencing a severe relapse of MS and she was also grieving and coming to terms with her mum's death. Josie explained she was 'weak and tired' indicating she did not have the strength to follow-up with the medical professionals at the hospital. Josie explained she was discharged from the hospital after a month and sent home to rest. This was done with no clear and concise discussion with a relevant health professional about her medical condition.

Liz (aged 35) had waited 14 years to receive a confirmed diagnosis of MS and had similar feelings of anger about doctors and specialists as expressed by Josie and Sammy. Liz expressed her annoyance at the long wait for a diagnosis:

"I waited for 14 years until I knew definitely what was wrong. It's tough going...it does make you angry, the way they tell you things, if they want to. When I got to the hospital for tests it was pretty quick to getting the results and finding out...it was a relief as I could name it, name what all these strange things had been...still are".

Liz expressed her anger at waiting 14 years for her diagnosis of MS. Liz stated that once she had access to a neurologist at the hospital the tests and results were conducted with speed. Liz had this to say about when she was given her diagnosis:

"I had been told what tests they were doing and what they were for. It was a female trainee neurologist who carried out the tests; I had a lumbar puncture, an

MRI scan and some electrode monitoring. I found her to be very honest and she explained to me everything they were doing and what each of the tests were for and what it would tell them about what was going on with my body and if I had MS... I had to wait 4 weeks for the results which was hard, you are thinking about it all the time everyday and you are imaging what it will be like to be told that it's MS...It was Mr Shepherd who gave me the results (it was his clinic I was under) and I sat down and he said 'I can confirm you have MS after the tests which were conducted on such a such date' my mind went blank at this point and I next found myself walking down the corridor towards the exit. I didn't ask any questions as I couldn't think straight and I was told to go back in 6 months"

Liz's tests, procedures and consequent diagnosis at the hospital were a positive experience for her. Liz was angry at the way her symptoms had been ignored for so long but she felt the hospital had acted quickly once she was in the system. She was one of the few women in this study who had had the tests procedure explained to her and she had been informed of what the specialist would be looking for in the test results. She also knew that she was being tested for suspected MS. However, when it came to being given the diagnosis of MS Liz was just read the results from her hospital file and not given any more information by the consultant. Liz further explained:

"At the time I went blank, I was panicked, stunned, all the things you expect to be and more, even though I'd known they were testing me for it, it was a big shock...looking back Mr Shepherd's trainee could have given me some time, talked to me about what the diagnosis meant, but he kind of gave the results, then got me out...nowadays they have MS Nurses who the doctor passes you on to, so I've heard..."

Jesse and Louise (who were the youngest women who participated in this study) both had short waits for their diagnoses in comparison to the other women and these women did feel that their experiences were unique. Louise had been dealt with very quickly and she describes herself as being fortunate. Louise said:

“I was very lucky to be dealt with so quickly. I do have a fantastic doctor’s surgery that referred me to the hospital very quickly when I was showing signs of not being well. I am a bit on the inside (laughs) because my mum works at the surgery as head receptionist so I think that contact helped in me being taken seriously – I know the doctors well and they have always known me since I was a child... They moved very quickly and I know that is rare now I have contact with other people with MS...the hospital consultant (Mr Majeed) was very professional and explained all the tests he was doing and the what, why and wherefore of them. I had my results in 4 weeks and was diagnosed with MS then... It was devastating”.

Louise’s experience emphasised that it is possible within current medical structures to obtain a diagnosis of MS within a reasonable timeframe. Louise and Liz’s experiences emphasised that hospital procedures can work for people. The women who had positive things to say about hospital procedures attributed this to consultants spending time with them and not making them feel rushed; explaining test procedures to them; offering them information about MS or directing them to other sources of information that may help them and being able to see the same consultant on each visit. For example, some of the women highlighted that seeing the same consultant on each visit to the hospital would result in a consistent care plan. It was also important that the same consultant was seen when carrying out tests and when receiving the test results. This was the main problem for Liz as when she received her MS diagnosis, it was just read from her file by a training neurologist (she thought). Many of the women felt that consistency would provide a more relaxed situation for people. Jesse’s experience at the hospital was also positive for her mainly due to the approach of her neurologist’s team. Jesse said:

“Yeah, once I was in at the hospital it was a comfortable ride to getting the diagnosis. I didn’t have many problems with the doctors at the hospital; I found them approachable and easy to ask questions to. Nice guys. I was told I had MS about 3 weeks after the tests had been taken, they did tell me what was happening, and what they were testing me for, so I had 3 weeks to think about MS and that I might have it, and what this was going to mean for me. It was still a great shock to be told I had MS, well it is isn’t it? But I had a good guy, good consultant, who was friendly and talked to me, he didn’t just leave me, like

some people, going away with questions, he was patient and I didn't feel like I had to quickly run out of the room. Yeah he gave me time which is what's needed when you have that kind of blow".

Prior to being referred to the hospital for further tests both Louise and Jesse experienced questions about depression and anxiety. Louise explained that her GP did question her on her menstrual cycle and symptoms of depression although this did not impinge on her being referred to the hospital for further tests. Jesse felt that the diagnosis procedures for MS were improving particularly as she had since talked to other people living with MS and realised that many people face years of trauma before being diagnosed with MS. Jenna (aged 42) felt she had a positive experience with the neurologist who gave her the diagnosis of MS. Jenna said:

"I received an appointment in the post for December. I told my husband not to bother coming with me as they would probably just check my vision and it would be a waste of time for him so I attended alone for what I thought was a routine visit. My consultant asked how my vision was. I said it wasn't 100%, just a bit of blurring, but that I could live with it. He then said "I can confirm that you've got MS. It was relapsing and remitting type and he couldn't say if I would be in a wheelchair in 5 years, 10 years or 20 years. He also said there was a very good MS nurse based in the hospital who sees people diagnosed with MS and would I like an appointment with her? I was asked if I had any questions."

Jenna further explained that she felt the neurologist was 'good with her' because of her background in nursing and management. Jenna felt that he treated her with respect because of her work experiences. Jenna does highlight however that the consultant could not offer any reassurance on whether she would experience disability – or how that disability would present and when. However, Jenna recognised that in most cases of illness you cannot predict what is going to happen and she said it made her think about some of the frustrated families from her nursing career. In this respect Jenna

recognised some of the tensions present between objective and subjective experiences of health.

Rebecca's (aged 46) experience of diagnosis was the same as Louise's, as she was diagnosed after 3 months with MS following her first symptoms. This was helped as her boyfriend's father (at the time) was a doctor and advised her on her symptoms. Rebecca was 21 years old at the time and the diagnosis took 12 weeks from her first symptom in 1981. Like Louise, Rebecca felt that her medical contact assisted in her early diagnosis. The key here was that both women had been referred immediately by their local GP.

However, contrasting with the positive experiences with hospitals were some distressing stories. Several of the women who were interviewed had had many years of visits to neurologists prior to being given a diagnosis of MS. Emily, like Josie, had visited specialists several times over a long period of many years before being given a diagnosis of MS. Emily highlights what happened on one occasion when she had an appointment with the specialist:

“Got in to see the specialist, and he sent me for an MRI – this was my first MRI scan ever. Went back to see them and they said you have some wear and tear in your neck. You know, go home. I thought ok, wear and tear in my neck, that's it, maybe arthritis. You go home and you get on with it. By this time I had a six year old and a five year old, you just get on with it, etcetc. I always had this weakness on my left side, always knew it was there but I just got used to it”.

Initially Emily was dismissed by the specialist as having ‘wear and tear in her neck’. At this point in her life she had got used to the weakness she experienced on the left side of her body and had adjusted. Emily continued:

“4 years ago in the August I was cleaning somebody’s fridge (I used to be a cleaner) and erm, I felt this tingle in my face the size of a penny. I thought aw, and it itched a bit and it lasted two or three weeks. And I’d gone to see the doctor about something else and I just happened to say to him I’ve also got this tingling sensation in my face, just a tiny penny shape, I wasn’t sure if it was an abscess or something. He said ok I will send you to see the neurologist and six months later again erm, I went to see the specialist (that’s about five years ago) and he said (after doing tests such as pins etc) he said we’ll send you for an MRI and we’ll see what’s occurring. So I never heard anything and six months later at the Christmas my face went numb on the right side, tingling in eyes and ears and went back to the doctors. I said this tinglings got worse. He said he would follow up getting an MRI. Never heard anything and then by the February, erm, my arms, hands had gone heavy and odd – couldn’t really put my finger on it but they were just odd.

Emily’s narrative highlighted the inconsistent service she was receiving from her local healthcare. After a tiresome experience of managing to get referred to the hospital from her GP surgery for specialist advice the appointments were slow in arriving and she felt that nobody cared about what was happening to her health. Emily continued: to change

“Went back to the doctors and I said you’re supposed to have jived up this MRI, and I found out they hadn’t done anything. They hadn’t jived it up at all. They hadn’t done anything. So this time I insisted on the letter being sent etcetc, so I got the letter confirmation sent saying that they were waiting for a quick appointment. Anyway a few more days went by and my face became very painful, very tingly and very painful. I was back at the doctors, and they were telling me the obvious, ‘you need to lose weight’, and ‘are you taking your Prozac?’ so I was really pissed off with the doctors by this point. But anyway I went one day with my mum because I thought a bit more support and they may not tell me I’m overweight, you know if my mums there. So I went to see this doctor and I said to him look my head feels like its been chopped in half, filled with concrete, and it’s all tingly, and I’m frightened to death, I don’t know what’s happening. I said to him I don’t know if I’ve got a tumour growing in my head, I don’t know what it is. By this time we had already gone through all this the doctor turned round to me and said ‘what you’re describing sounds like stress. I suggest you go home, forget about it, and you try and de-stress’. With which I just my bag up and walked out”.

Emily had been passed from pillar to post until she finally demanded that her appointments be organised properly. Only then she was faced with further humiliation by the doctor when he told her she was experiencing stress. Emily's story of misdiagnosis details a sorry turn of events that left her feeling alone, confused and unsure of what she was experiencing. It was a further 2 years before Emily eventually received her diagnosis of MS. A similar story was echoed by Suzanne (aged 45). Suzanne outlined her experiences at the hospital below:

“We moved and I was still getting these problems in my left leg on and off, and after a lot of nagging from me my doctor sent me to a neurologist in Wrexham, as that was our nearest hospital at that point. Erm he was called Mr Smith, who is a horrible man. I went to see him and his sidekick. He did some tests and that and he said we'll do an x-ray on a certain part of my spine – can't remember exactly which part – anyway went back a few weeks later for the results and he said oh no couldn't find anything, we tested you for MS and basically he said 'I'm not saying you're making it up' so basically he was saying it was all psychological. He said come back in six months but I just tore the paper up because I said to my husband I am not going back to see that horrible man ever again”.

Suzanne felt that the neurologist mistreated her. She described a situation where she felt embarrassed and made a decision not to return to see him again. Suzanne finally received a diagnosis of MS 3 years later when she booked in with another consultant. Suzanne recalled the time of her MS diagnosis where she felt compassion was lacking from the consultant when given her diagnosis of MS:

“I got my MRI scan on the Monday morning. A consultant spoke to me briefly about the results saying it was possible I could have MS but didn't explain what that was. I remembered reading an article about the DJ Stuart Hendry from Radio Luxembourg (at least I think that was his name) who had MS, deteriorated rapidly, was in a wheelchair and died before his time. That was the image MS brought to mind so I preferred to tell myself that wasn't what I had. I was told I would be sent an appointment to review the situation at a later date”.

Suzanne highlighted that she was not given any information about MS when she received her diagnosis. Like Emily, Josie and several of the women hospital procedures for the discovery of MS did not work for Suzanne and left her feeling angry whilst still living with the symptoms of MS.

The women's stories of a diagnosis of MS all had a similar theme. The majority of the women had experienced symptoms of MS for a period of up to 27 years and many of them held the belief that depression and anxiety had caused them. So much had the women been affected by their long-term period of living with MS yet having a diagnosis of depression and anxiety they found a diagnosis of MS difficult to comprehend. This had particularly impacted on the older women in the study.

Older women and the impact of a diagnosis of MS

As outlined so far in this chapter many of the women in the study had visited doctors and sometimes specialists with their symptoms and health problems. Their symptoms of MS had been diagnosed as hormonal problems, anxiety problems or depression by their GPs, which was a finding in all of the women's experiences with GPs. However, for many of the women in the study they had huge problems when they eventually received a diagnosis of MS – especially the older women who had lived for the longest time with symptoms of MS and with no diagnosis of MS. Initially these women found a diagnosis of MS confusing and could not comprehend what had happened to them. Several of the women suggested they had accepted they were depressed and felt confused with a diagnosis of MS. Doris (aged 67) outlines her thoughts below:

“For years I thought I was nervous-maybe I am, sometimes I'm not sure, but to then find out it was something else, is something else, is distressing. It's hard to

take that, take in, you know, to understand what's happened. You see love, I don't know what I have, or what's been wrong with me, or what is still wrong with me. I know its MS now, and that's why I use this stick, and why I am tired and sore and my legs hurt. I understand that now and I've read some things and the family have read some things for me to help me. But then I don't know if the depression is part of that, you see the doctor told me that for a long time, and I get mad with that. Sometimes I get cross because I think who are you (in reference to the GP) to decide what I've got".

Doris displays her confusion in her narrative above when she says *'You see love, I don't know what I have, or what's been wrong with me, or what is still wrong with me'*. Doris acknowledges her diagnosis of MS but still has difficulty understanding the many years she spent visiting her GP who diagnosed her with depression. Doris shows this when she says *'But then I don't know if the depression is part of that, you see the doctor told me that for a long time, and I get mad with that'*. Doris had spent 20 years of her life experiencing the symptoms of MS and being told by her GP she had depression. Doris had reported the symptoms to her GP over the years. This is what she said:

"...I went to my doctor a lot with things like balance, sometimes I would stumble and afterwards I would always have big bruises on my legs, you know, where I had bumped into furniture or doors. I asked the doctor once about slurring my words sometimes, and he said I probably had migraine, yeah, migraine he said. And that was the end of that... One bad episode was when my sight was bad, which then made my balance worse, and my calf, ankle and foot were sore, nothing made them better, not a hot bath or rub or anything. I mean they were agony and it lasted for a good month, that type of pain. I got no joy from him, just said it was migraine again and that this was linked to the depression I was having. He said to me once when I went with bad pains in my muscles in my neck that it was my posture, and because I was depressed, I was probably slumping my body. You see, people do hang their shoulders down when they are feeling down, I remember telling my girls to stand up straight and walk with you head up high".

This tension was reflected by a number of stories told by the women. The women said they went through a period of shock that left them feeling disorientated once they had a diagnosis of MS. Doris outlined how she managed to get her diagnosis of MS:

“We got a new doctor at the surgery and he looked at me one time, when I had my bad leg, which I carry my MS in, that’s where it gets me, and this leg has just got worse and worse over the years, and he thought hold on what’s going on here? He asked how long my leg had been like this for, and a few other questions, and he asked about these other things I had been getting, and he said I think you need to go the hospital. So he got me in quick. I was getting worried at this point cause I was thinking this is all a bit quick; maybe they think I’ve got cancer or something, anyway, I got in to see Mr Granger, and he said straight away, I think you have MS and I’m going to check this for you by doing some tests for MS...2 weeks later it was confirmed. He was very nice to me and I asked him about MS and how long I had had it, and he said from looking at my history I had signs of it for many years. I clicked then that all these odd things over the years had been the MS”.

Like Doris, Iris had experienced MS symptoms a large chunk of her life course. It was 25 years of living with MS before Iris knew that her symptoms were those of MS.

Iris explained how she came to be referred to the hospital for tests:

“There were a good nurse who were checking my bloods, and she asked me a few questions, and it came up about the symptoms, and she listened. I didn’t feel worried to tell her, I was about 47/48 by then, I was going through the change, and that’s why I were having my bloods done, the kids were grown up, and I didn’t feel stupid I suppose anymore. So all the symptoms, the soreness, the pains and that, which had all got worse over the years, but then I did have a couple of really good years where it went away, but always, always came back, if I ever thought to myself, they gone now, it was like tempting them, and sure enough there they’d be...

...So, the surgery had like 3 doctors by then, it had grown over the years, and I saw this younger doctor, and the nurse had already told him what I’d told her, and so he was ready for me, and he wanted to know about all the years of me having these symptoms, and how often, and like I’m doing with you now, I had to try and remember, and it was foggy in places, like it would be, you know, but I loved the fact it was all coming out and he was listening.”

Iris expressed this by using humour and an almost flippant explanation of her absolute confusion at her eventual diagnosis of MS after experiencing symptoms for 25 years:

“...I mean what do you do with it? At first I thought they were saying I had something extra as well as anxiety, then they said it was probably all MS, then some cheeky young doctor said people with MS do get depressed-I said, well they could only get depressed if they knew about it!” (Iris aged 71)

Iris's expression here of *“some cheeky young doctor said people with MS do get depressed-I said, well they could only get depressed if they knew about it!”* highlights the confused discourse from being told for many years that she had a diagnosis of anxiety and depression to be told that she did in fact have MS. It also brings into question the origin of some of the medical symptoms of MS and what they actually mean. Also Iris's character came across as using humour to express quite distressing situations, and this occurred throughout the interview with Iris.

Sontag (1991) examines the translation of illness and sickness through the use of metaphor. Sontag (1991) recognises that illness becomes constructed within the socio-cultural dynamics from which it is produced thus reflecting the institutions of that particular society. Similarly, Foucault's (1988) concept of 'disciplinary technologies' suggests that practices become engrained within state systems and reflect the power base of that institution. Frankenberg (1992) recognised that epidemics of illness are constructed within the boundaries of the time and space in which they occur. In this sense, epidemics of illness are co-created with 'disciplinary technologies' which serve to act out and coerce the created reality of illness. Frankenberg's (1992) understanding that chronic illness and disability is often overlooked, ignored and misdiagnosed is useful for thinking about some of the experiences of misdiagnosis and MS. Frankenberg (1992) suggested that chronic illness is often overlooked by the

biomedical model due to the challenges it poses to the authority of medicine. In essence, chronic illness challenges the already reinstated disciplinary technologies. Frankenburg (1992) recognised the challenges faced by medics when people present with symptoms that are not fully understood or clearly mapped out within medicine. Explanations are sought to explain what is occurring and the limits and boundaries of medicine encourages the expression of cultural and social discourses. Martin's (1989) assertion that women's bodies are culturally adapted in medical authority as a form of understanding is useful here alongside Frankenburg's (1992) understandings of medical authority. In the cases of the women in this study it is apparent that their symptoms of chronic illness have been overlooked and furthermore, their symptoms of MS have been understood as depression, anxiety and hormonal problems – as reported by all the women in this study.

The women expressed their concern at experiencing symptoms for a number of years before a diagnosis of MS was given. 4 of the women had since found out that a diagnosis of MS had been written on their medical records up to 20 years before they were told they had MS. Some of these women had also found out that their husbands or partners had been told of their diagnosis but were subsequently informed by the doctor not to tell them as this could accelerate their condition. Doreen (aged 67) outlined this scenario:

“When I got my diagnosis (she was 50 when told by a neurologist) it was casually given by this neurologist I had been sent to. I was really confused about it and a few years ago, you know, when it became legal to look at you doctor records, I looked at mine and they said ‘suspected MS’-this had been written when I was in my twenties. I was really angry cause I since found out my ex-husband knew and the GP had told him not to mention it to me as they couldn't do anything about it”.

This was difficult for Doreen to accept as her marriage had broken up and she had always been on bad terms with her now ex-husband. For Doreen she felt like she had been robbed of her own decisions and said she felt 'disgusted' that her ex-husband had always known about her MS and she had not.

The women explained that being diagnosed with MS did not alleviate their distress about what was happening to their bodies. They felt betrayed by their GPs and also let down by their partners and husbands who had been aware of their prognosis. On reflection they had felt like second class citizens and explained this in the context of their life experiences. For example, Doreen explained:

"I think what hurt the most was Eric knew and he never told me. Our whole marriage he used to ignore me (about my health and symptoms of MS) and tell me I was mad - I now understand why. The bloody doctor had told him as much. I feel like my life has been a fraud for all them years...yeah, that hurts the most"

Doreen explained the emotional impact of having her diagnosis of MS withheld from her. Iris explained in her interview that her neighbours were told that she probably had MS but there's not much that can be done about. Iris told the following story:

"I forget the proper details about this, but it happened, I just can't remember exactly when, where, all that detail stuff. My memory gets slow sometimes, you want to start writing things down Louise whilst you're still young an that. **(Laughs - I remembered yer name this time!)**. Well one time I were at the nurse clinic, it's attached to the doctor but you see the nurse instead, that kind of thing. The kids were still at home, our Janet was probably about 13 something like that and Cassie, my friend over the way came with me to the nurse cause she were worried you know about what I were getting an that. And this nurse said to her, (Cassie), when I had nipped out to do a water sample, she said to Cassie, they were chatting and Cassie were saying that I get these things all the time and it's not right, and the nurse said something about me having MS but they can't help me and it's best if you just get on with it, and not to tell me as I

might go worse. Well Cassie were worried at this as you can imagine, and told me when we'd left about what the nurse said. The thing was she was unsure if she said MS or something else, so we just had a laugh about it, you know, cause she couldn't remember to tell me, the medical name..."

Iris's narrative above emphasised the bad practise of the nurse as she should not have been discussing Iris's health records with her neighbour. The nurse had also made the decision, along with the many GP visits that Iris had attended to not inform Iris that she had suspected MS. Iris recognised that it was wrong of the nurse to disclose this information about her to her friend yet Iris and her friend coped with this information by using humour to alleviate any potential serious consequences attached to the information.

6.3 Emotional responses to receiving a diagnosis of MS

The women expressed their emotional understandings of having a diagnosis of MS after experiencing symptoms for a period of years. There were key issues raised by the women that were identified as being emotional responses. These key issues were:

- Anger and grief at finding out they had a chronic illness which is currently incurable;
- Anger and betrayal at the medical system – specifically with doctors from their local surgeries;
- Fear from not knowing what the future held.

Many of the women discussed the impact of believing they were depressed to discovering they actually had a neurological disorder (as discussed in the previous section particularly in relation to the older women in the study). The women expressed feelings of anger, turmoil, frustration and betrayal at the medical system.

They recounted numerous stories when they had felt ridiculed by health professionals when attempting to gain some clarity over their condition and their health. Some of the women who had waited over 20 years to find out they had MS indicated they had spent a lot of time going over the years they had lived with MS not knowing what it was. They had found it difficult to manage at times and they showed that they still held emotional scars. Doreen expressed this below:

“I remember being a young woman, about 27, and I had lost the feeling in my right arm and was limping in my right leg. I was so frightened as I thought I must have had a stroke or something. When I told the doctor he looked at me puzzled and asked how my periods were. I said they were fine - I ended up leaving his room with a bottle of pills to make me relax”.

The women had approached their local doctors with bladder problems and were told that problems with ‘their waterworks’ should be expected after having children. Over time the women eventually managed to get a referral to a neurologist. The women acknowledged this to be indicative of changing times for women and of becoming more valued and ‘treated like a person’. Emotionally the experience had left the women drained. They felt that they had missed out on trying to get well by not knowing what had been wrong with them. The women also felt deceived at many levels and did feel like they had been exposed. Doreen said:

“It’s a feeling of loss when you find out exactly what’s wrong with you because to be told you have MS is a bit frightening. You know, it’s not good but neither is realising that they knew what was wrong with you all the time. That’s feels horrible. You can’t explain it. You just can’t. How do you? Where do you start? They know what’s wrong with you but choose to not tell until they want to. It’s like a circus, a freak show, but we are meant to be good people in this country - aren’t we? ”

Doreen remarked that to not be told what illness has been diagnosed *'feels horrible'* and expressed her staggered response when she says *'You can't explain it. You just can't. How do you?'*

All of the other women in the study who had waited over 7 years for a diagnosis of MS still reeled that they had waited so long for a diagnosis and felt that there should be a more efficient system in place for people with MS. They felt that psychologically the wait had impacted on them. Many of the younger women had already worked out for themselves what was wrong with them with Josie saying that the diagnosis just gave her the validation she needed to know that she was right. She was only in her 20s when she was experiencing MS symptoms and she says that she would go to work then fall asleep when she got home. She says this was not normal for her age and knew there was something seriously wrong. Being diagnosed gave her relief and confirmation.

For some of the women the way they received their diagnoses of MS left them with a mixture of feelings. Emily's narrative here is a good example of this.

"So I had been a bit of pain at the doctors, going and saying do you have my results, can I have my results, and then I finally rang the hospital erm, and I got a letter from my consultants on the 28th May to say you will get your results from the hospital on the 4th July. And I thought I can't wait that long to find out if I'm going to die. So I rang them up, I said I cant wait til that long to find out if I'm going to die or whatever, and she said actually we have got a cancellation this afternoon, so I took it. So at 3.00 on the 28th May cause that date is stamped into my head I walked in to see the consultant, me and my mum. He sat me down and said how are you? I said well I have been better, hoping not to get worse but have been better. He said have you any idea what you've got? So I said well I think it's MS, I'm hoping it's not motor neurones, so I'm hoping it's MS. And he turned round and said 'yes it is'. I went oh. The tears just rolled down my face. He looked at me and said 'are you alright?' how I didn't swear I don't know, I do tend to swear (laughs) and I said 'at least I'm not mad'. Cause by this time I'd convinced myself it was all in my head mum kept saying to me are you sure, she was going to pay for me to get my thyroid done and that. When

I got my diagnosis of MS I said to the neurologist – well at least I know I'm not mad now. He just looked at me – the one thing I remember is he gave me no information, no one else to talk to, and you know what he didn't even have a box of tissues. I always remember that – no bloody tissues. When I cried he turned away but luckily my mum was with me to offer some kind of comfort”.

6.4 Exploring age and experiences

Taking into account the structural and economic disadvantage experienced by women over time, the younger women interviewed tended to engage with medical authority from a higher level of awareness about their bodies.^v Several of the younger women interviewed discussed their relationship with medical professionals in a critical way and had challenged the knowledge's they had been presented with. This could be an indicator as to the shorter length of time between disease onset and disease diagnosis. It could also show the changing experiences for women generationally.

For the younger women who were interviewed a critical reflexive approach to their bodies and medicine was discernible in the stories they told of their health experiences. They did not always feel oppressed or inscribed in the medical regimes offered to them because they now felt in control of their health. Although several of them had initial negative experiences with a medical professional they felt they had managed to move on past that and enter a 'fight for life' stage.

The younger women in the study had all tended to partially recover from their ordeal of not knowing what was wrong with them, to receiving a diagnosis and in turn taking on a 'fighting back' attitude. This came out in Josie's story as she said that *'...once I knew what was wrong with me I thought there is no way I will take this anymore. I want the help I'm entitled too'*. Sammy also showed a similar attitude saying *'...I can*

recover and get past the anger, you know, of not being listened to all that time '. This is an interesting position posed by some of the women as it identifies they have responded to their mis-treatment in the medical system. For example, Josie and Sammy are currently involved in telephone support for people who suspect, or have recently been diagnosed with MS.

All of the older women discussed their experiences with medical professionals as a changing relationship which they identified as being located in particular times and spaces. As highlighted by Doris (aged 67):

“Years ago I respected doctors. Now I distrust them. If I know them, than I’m ok but put me in a room with a strange neurologist for example and I would just shut up. Either that or walk out because they are mostly arrogant and when you get old, like me, they are just not interested. They are waiting for you to die”.

Similarly several of the older women expressed anger about the way they had been left to deal with something they did not understand. Some of the women were quite forgiving towards GPs and recognised they could not be held responsible as it is just their job. The older women’s anger was placed around their past lives and around their situations. Many of the women said they felt bitter towards their husbands for a lack of support and because they never took them seriously. They placed anger around issues of patriarchy and a feeling of powerlessness.

Summary

Chapter 6 highlighted the long time scale the majority of the women experienced from the beginning of their MS symptoms to a diagnosis of MS. Many of the women pinpointed that the reason for this was due to their local doctor’s slow referral to see a hospital specialist.

Once in the hospital system the women reported a mix of both good and bad experiences with specialists or neurologists. Not all of the women had had bad experiences with specialists or neurologists but they had all felt that the provision of service could have been better. For example, the information on tests being conducted would have lessened their anxieties during the waiting period from test to diagnosis. The women had also felt that they should have been able to have asked lots of questions but for various reasons they felt they had not been able to. The majority of the women had lived with MS for many years before having an understanding of what was happening to them.

Chapter 7:

The women's experiences with accessing health supports and services

Prologue

Chapters 5 and 6 outlined the journey from the onset of MS symptoms to receiving a diagnosis of MS. Chapter 7 furthers these discussions by examining the women's experiences in relation to health supports and services. Through exploring the women's narratives 6 categories were identified reflecting their experiences with health supports.

Chapter 7 raises questions within and around women and MS directing the reader to thought provoking insights into the reality of a chronic illness and the disconnected understandings of medical and personal discourses.

Introduction

Chapter 7 represents the women's encounters with the lived realities of accessing healthcare and outlines the women's access to health supports and other identified care issues as highlighted from the interviews. Chapter 7 specifically examined care practices once a diagnosis of MS had been given. Furthermore, Chapter 7 discusses any prevalent issues or limitations within a context of health and service provision for MS.

Interpretation of data collection

The women's narratives showed that there were similar, recurring, medical and social care theme issues that impacted on their lives and these are presented in table 7.1.

There were also some specific key findings in relation to age and these are highlighted throughout Chapter 7.

Table 7.1 displays the theme of Medical and Social Care Supports

Theme: Medical and Social Care Supports
↓
Sub themes
1. Local healthcare supports
2. Access to a neurologist/specialist in MS
3. Choice to treatment of MS
4. Travel and medical care
5. Gatekeepers
6. Expectations of care

7.1 Medical and Social Care Supports identified by the women

1. Local healthcare

All of the women had a local GP practice where they accessed a doctor or community/public nurse when required. It was common knowledge with the women that unless the doctor had a specific interest in MS he may have very little knowledge about new drug developments and treatments^{vi} Most of the women described positive relationships with their GP although some of the women suggested that they did have problems with their GP when trying to access specialist care. For instance, Josie was happy with her current GP who she had seen since her diagnosis of MS (Josie had changed GP practices due to her negative past experiences). Josie said:

“My GP is ok and friendly enough although I do feel like a pest sometimes. When I asked about a referral to one of the MS Specialist centres he felt that I should go to my current neurologist to request that. The thing is, as if I am going to confront the only person treating my MS by asking him for a second opinion elsewhere –so obviously I have not...I should have pushed him to refer me but that particular day I was feeling down and I just didn't have it in me to start going on. You have to be in the right frame of mind and I wasn't that day, but I will another time...although he is a good GP and a lot better than my previous one, but sometimes I would like to feel that he's with me, and understanding where I'm coming from.”

Josie highlighted a point that was flagged up by several of the other women. Some of the women suggested that GPs did not have awareness about what was on offer for people with MS. Another example, provided by Sammy outlined the frustration felt by some of the other women:

“Have you ever had that feeling, sore ears, bursting, room spinning, vertigo feelings anyway, well, I had, at the beginning, well, once, quite bad, since I have been diagnosed with MS. The kids were babies then, well toddler and a baby, and I went to the doctor cause my balance was very off, and my ears were just ready to burst, he said it sounded like stress. I asked him if it could be my MS developing and he said no - firmly. I went home, and a few days later,

it came back with a bang, I couldn't stand up for long and the sickness, you know nausea, and I was sick too, and my head and ears were in agony. I went back to the doctor, and this time got to see my usual doctor, who's a lady, and she was sympathetic, and gave me some pills for vertigo, but she said that vertigo is nothing to do with MS, and that you get vertigo, when you are overdoing it, and getting stressed, like the other doctor had said. I have since though asked my neurologist about the vertigo and he says it is a symptom of MS and gave me another med for it. It's this kind of thing that annoys me, telling you different stories, and conflicting each other".

Another instance outlined by Doris:

"I go to the doctor, and have done as I've said, and now I have a younger doctor, not the same one from years ago, cause surgeries change and that, and he's nice enough, but I think they just see me as written off now, and nod when I go in, and offer pills if they can, but it doesn't feel like I'm going for support, it feels like I'm going to moan and I don't want to waste their time either...I suppose he doesn't know what to do with me...it feels like I'm on my own with it and going to see him can make me feel more on my own, cause you wonder why you've gone".

Doris's narrative highlighted her frustration at attending her GP and recognised that the interactions did not satisfy her support needs. Like Josie's and Sammy's narratives, Doris's narrative suggested that the GP and patient consultation did not always prove fruitful and often left her feeling further isolated.

Some of the women who used local services had found if the staff working in these areas were keen to learn more about MS and actively wanted to improve care for people with MS this proved to be a rewarding experience. Emily (aged 42) outlined a positive experience in physiotherapy:

"I go to the local physiotherapy unit and I find that they take an interest in getting to the route of my disability I have. They want to help me live comfortably and make me feel that they want to learn about what MS is like to live with. You know, erm, they try to learn about the symptoms that are difficult

to explain, they don't make me feel like I'm making it up or exaggerating...you know, that attitude helps me a lot".

Most of the women were able to access physiotherapy at the local level. This could be easily arranged on a referral from the GP. However, some of the women felt that if the physiotherapist did not understand the wide and varied symptoms of MS it did impact on the physiotherapy treatment. Like Emily, Josie reflected this attitude:

“Because pain is such a main symptom for me I need to know that the person working with me understands about MS. I once had a physio who said the pain wasn't related to MS and they continued to work with me whilst dismissing the pain I was in. I never realised how uncomfortable that experience had been until I worked with a physio who knew a lot about MS and they approached my body in a totally different way. And the benefits I felt afterwards were amazing”.

2. Access to a neurologist or specialist in the field of MS

Access to a neurologist or specialist was significantly different between the younger group of women and the older group of women. The following table 7.2 displays the current information on the women's access to a neurologist.

Table 7.2 shows the women's access to a neurologist or specialist

	Regular access to a neurologist or specialist	Requested access to a neurologist	No access to a neurologist or specialist regularly
Number of women	7	All requested at some point through their G.P.	9

Table 7.2 highlights that 7 women had access to a neurologist or specialist. This was on a 3 month, 6 month or yearly basis dependant on the progression of MS and their medication. Those women who were on the self-injection treatments of Beta interferon (please see appendix 1 for BNF description) and Copaxone (please see appendix 1 for BNF description) had more regular appointments (see Chapter 2 page

12-13 for further information on the medications). For example, Rebecca had regular access to a neurologist and she was also on Beta Interferon. Rebecca also worked in the NHS and had a good knowledge of what she could obtain. Linda from the older group of women was not on any specific treatment plan but was a local campaigner and regular speaker at the teaching hospitals in her local area. Linda managed to see a neurologist when she required one.

Significantly 9 of the women had no regular access to a specialist or neurologist. At some point in their health pasts the women had had at least a single visit but many of the older women had not seen a specialist health professional except their GP for a number of years. This had a big impact on how their MS was monitored and left many of the women feeling frustrated. On the one hand they were experiencing a debilitating body which was unpredictable most of the time, and on the other hand they had no expertise knowledge to offer guidance or explanation to them. Iris encapsulated this experience:

“I don’t see a neurologist at the moment. Like, I don’t have regular appointments or anything, but maybe I could if I asked, to be honest, maybe I could. I think that it could be a waste but maybe if I’d seen one the whole way along then that would be different, like it might have helped me, cause I spent a lot of this illness not seeing anyone, so then you don’t know, do you, what the difference would be if you had...does that make sense?”

Iris questioned that as she had never had regular access to a neurologist then would it be appropriate for her to now? Doris (aged 67) had a diagnosis of secondary progressive MS (SPMS) and spent most of her time in a wheelchair although she could use a walking stick for short periods of time. Doris was diagnosed at the age of 40 with relapsing remitting MS (RRMS) although she could trace her symptoms back for 20 years. Doris recalls that when her MS progressed it took 4 years for a medical professional to respond to her changing needs. She was then diagnosed with PPMS

and then SPMS. For Doris these distinctions between the types of MS were important and she felt desperate that it took so long to identify. Doris outlined:

“I’ve been in the chair now, eck, it must be 15 years I think, when I’m here (at home) I can sometimes use a stick if I’m up to it, but without my chair it would be hard going. When it first deteriorated it was quick, no warning signs, I just lost my walking within a week. At first I thought it might come back, cause people can with MS. It comes and goes, but after a while I was told the MS has turned into primary progressive MS, and now I have secondary progressive. I battled away at home though, not been able to walk, for over a year before I was told that it were primary progressive. And in that time the help I got were not enough. I was stuck in a rut and couldn’t get going about my day because everything was about waiting to see if my legs came back. That’s what the GP used to say. See if they come back before we start pushing it, but that didn’t help me, but I was too upset to keep going. It took me a while to accept it wouldn’t return, or to anything like it was, and it took even longer for me to get the supports I needed. I needed to speak to just 1 person who I could tell what I needed, but you get passed here and there, and you have to keep telling the story, and then it gets so bad, cause your tired as well, that you think, sod it, can I be bothered...it took me 4 years to get what I needed to live easier”.

Doris’s narrative highlighted her frustration at not having her needs met when the trajectory of her MS path changed. Doris emphasised her loss of control over her life when she said ‘*And in that time the help I got were not enough. I was stuck in a rut and couldn’t get going about my day because everything was about waiting to see if my legs came back*’. Doris outlined that the transition from RRMS was not dealt with effectively through her local health care providers. Doris also felt confused about the various types of MS. She declared that she currently had SPMS after experiencing PPMS, although the usual pattern would be the other way round. Also, Doris felt that her GP had not linked her up quickly enough with a neurologist, and had waited to see how her symptoms developed. Doris said this time period was significant and was unhappy it had taken her 4 years to clarify.

Choice around treatments of MS

There are currently 2 main treatment plans for people living with MS. These are called Interferons and Glatiramer (see Chapter 2 for a further description, section 2.2). The development of these treatment plans has been, and continues to be, presented as a form of hope for people living with MS. Generally, it was the younger women in the study who had information and knowledge about the new treatment plans. Many of the other women were not even aware of these new treatments for MS so therefore many did not even enquire about them. Notably, the older women in the study had not been provided with information about treatment plans for people with MS. For example, Doris (aged 67) commented:

“I know that there is no cure for MS, just different pills that the doctor thinks might help. I was watching something on the tele and this woman had MS and she was being given these injections to help. They made it sound like it was a cure, you know, but I don’t think they are real, or I’ve not heard of these injections...”

Similarly Doreen (aged 69) said:

“My niece told me about these new drugs that you inject that give people back their lives who have MS bad...I asked my GP bout them but he said they were for younger people, to stop them getting bad, so I don’t know, I don’t think there’s much for us old ones”.

Doris and Doreen’s narratives are examples of the older women’s understanding of current treatments for MS. Similarly, Iris commented:

“As I understand it once you’ve damaged that area on the brain with the MS they can’t get that bit better. So my leg can’t improve because that bit of me brain is damaged all the time and they can’t change that. I read in the Express about MS cures, people getting out of chairs because of these medical people and their inventions but I don’t believe that. How could they do that?”

Doris, Doreen and Iris had not been informed about any specialist treatment plans for people with MS. Even when Doreen had enquired to her GP about them through the information given to her by her niece she still was not given any information from her GP. This was not a particular issue for the older women as their expectations of care were extremely low. They generally accepted their position of an illness trajectory and felt that they would be excluded from any new and innovative treatments due to their age. As Doris (aged 69) explained:

“When you get to my age you know that you are not getting any better. Any chance of a cure is going to miss people my age now so we should leave it for the next generation. For you Louise (referring to me) they may find a cure and you will be ok”.

Similarly Iris (aged 71) echoed:

“I don’t think I would expect money to be spent curing me now anyway. I have had my life and should be relaxing into whatever time I have left. I don’t worry now too much about it – as long as I can have a fag and the odd drink that’s the only medicine I need...(laughs)...I mean I will see people, you know at bingo and that, and they say ‘oh I read this or I read that about cures for MS’ and I know they just being kind because they probably think I need help in that way, but really I am quite happy to get on with it, and that’s from the heart, my heart, that’s how I feel about it now, I don’t need to know about new stuff”.

And Doreen concluded:

“I’m not saying it’s the right thing but medicine is not looking to cure us old ones – the scientists concentrate on the young ones to give them a chance. What could they do with my old body now?...I bet you think I’m being negative about myself, I don’t mean to be, but you have to think about what’s going to be happening, and I know I’m going to be staying like this, which now I’ve got used to i have to say I can live like this now, I don’t like the pain, but I can cope with where I’m at, you know, I can do, I don’t feel sorry for myself, it’s a waste of time, I see people who waste time wallowing, not me. that’s not the way I am”

As highlighted in these narratives, the older women regarded this as normal procedure for older people. They gave other examples of health experiences their friends had

had to justify their thinking around this. (Doreen said that many of her friends had bad health such as arthritis and diabetes and they expected to be down the bottom of the list when it came to distributing NHS money). The older women also drew on a fatalistic approach to their bodies. For example, Doreen said:

“It’s going to happen anyways isn’t it? Getting old, getting ill with something, so you expect to be ill and not like you used to be. And it would be a waste of money now to start trying to mend my body, I’m past it, and I couldn’t be bothered – that’s life!”

Similarly Iris said:

“...oh it’d be daft trying to sort me out now, I’m too old now, and I want to get on with it. I have to die of something, and the chances are I’ll not get much else now, if I’m lucky, so let’s make the best of it (laughs)”

The women who had enquired about the main treatment plans for MS, and had been provided with the information, had had a long journey to either a yes or no answer.

Alison (aged 39) attempted to find out about being prescribed Beta interferon (please see appendix 1 for BNF description) or Copaxone (please see appendix 1 for BNF description) and went through the following scenario:

“I asked to be referred to the Walton centre in Liverpool. I know it’s the nearest specialist place and my GP said he would refer me. I don’t have a particular neurologist at the moment. The last time I discussed my MS with a consultant I was told I had relapsing remitting MS so I knew that I could be helped by one of the treatments (I had read about it in MS Matters). I went and they did some basic MS tests and then confirmed that I had in fact primary progressive MS. I had secretly suspected it was getting worse but I was shocked to hear it. They told me that there is no current treatment plans for primary progressive MS and that I wouldn’t benefit from Beta interferon (please see appendix 1 for BNF description) or Copaxone (please see appendix 1 for BNF description). I am devastated actually as I am left with no hope”.

The picture Alison described reflected confusion and despair which was shown in one way or another by all the women throughout their interviews in relation to medical practices. Alison's story represents a lack of awareness and consistency about MS from medical services at the local level. For example, Alison's GP had been unable to deal with her MS progression and identify the move from relapsing and remitting MS from PPMS. This story was not uncommon and similar situations were identified by several of the other women. For example, Sammy outlined:

“Initially, I wanted to find out about all the options for MS, but I personally found it very difficult to get the information. There are 2 key drugs that they use, or did do when I was first diagnosed, (You know, the interferon's and Copaxone (please see appendix 1 for BNF description)) and it was near impossible to get the information I wanted about them. I find that now, most people with MS, don't know what these drugs are or how to access them...now I am on the beta interferon, but still now, I would like more chance to chat about it, is the right thing for me, is it making a difference? Some days I really wonder about the impact it is having on me, long term, you know, but they just shrug the shoulders”

4. Having to travel for medical advice and care

If the women wanted to access specialist MS advice, for example, at a hospital where there were specialists who were experts on MS, they outlined that they would have to travel. This occurred when the women requested seeing a specialist who had a specific interest in MS. Liz (aged 35) explained this point:

“At my local hospital (which is 20 miles away anyway) I realised, by chance after a brief conversation with the nurse that the specialist I was seeing was not an expert in MS specifically. He deals with neurology generally but his interest was in Parkinson's disease, which you think, ok, it could be similar, but, I wanted to see somebody who deals with MS and that is their focus medically...to see a specialist who is an expert in MS I was told I would have to travel over 50 miles and before that I would have to wait in a long queue for an appointment”.

Liz, Josie, Louise and Sammy from the group of women had all travelled further than their local health resources to have an appointment. This meant they had travelled by car or public transport for over an hour. Josie had travelled over an hour and half for appropriate health care when she was pregnant. She had taken part in an outpatient study about women, MS and pregnancy, from one of the top neurological centres in the UK and she had to attend appointments every month and then every week for the last eight weeks of pregnancy. Josie said:

“I took part in the study because I felt more secure about having the baby. I was concerned that I would become more ill as my GP warned me this could happen. The specialist centre made me feel positive about the pregnancy and assured me I would in fact improve health wise during it – and I did...I learnt so much about MS from the staff and they, they had an interest and , they, they they really wanted me to do well, they were concerned but hopeful...and that helped me through”

Josie also explained that she felt more secure having the extra monitoring of her health and pregnancy and commented that as the staff were very reassuring towards her, which made her feel more confident during the pregnancy. Josie continued:

“I know the travelling was a pain – especially at the end when I was so heavy, but I would recommend taking part in a study, especially a pregnancy one, because it made me feel like I was trying to do something, you know, it helped me. I gained a lot from taking part, and I learnt more about MS than I had from my doctors, or even my neurologist, and dare I say it, even the MS nurse. The team carrying out the study were interested and they wanted me to get through the pregnancy, and be the best I could afterwards...so I didn't mind the travelling when I was getting all that support”.

5. Gatekeepers

The women identified that access to appropriate health care could be influenced by gatekeepers. For example, one of the younger of women Louise (aged 21) said:

“There are problems with gatekeepers and talking to the right people. You can get through but it takes time. Of course, travel may be involved, and that again is time consuming and frankly quite irritating. I pursue the issue if it is important to me and my health – I don’t have a problem doing that”.

Another example from Gill (aged 54):

“A few months ago I became aware of Beta interferon (please see appendix 1 for BNF description) and its usefulness in secondary progressive MS. I asked to be referred for it and it was impossible to get past the first post so I am still none the wiser”.

There was an obvious division between access to local health and social care support and to obtaining specialist support, such as a neurologist or MS trained nurse. For example, most of the women, like Gill, felt that getting past initial gatekeepers effected how they accessed health provision. This was experienced differently by the younger group of women as they appeared more informed (and generally more confident) than the other women. For example, Jesse (aged 26), like Louise was more confident:

“Now I have a good doctor’s practise and most of the doctors are friendly and easy to talk to but I want to be listened to and I know for example that I can insist on a second opinion and I will use it if needed. People don’t like to kick a fuss up, I don’t, but I would ask for a second opinion if I wasn’t happy with what I was getting”.

However, some of the women highlighted that the introduction of PALS Managers in local areas had enhanced service provision although this was specific to certain circumstances, such as knowing about the PALS Manager.

Many of the women were unsure about what services were on offer and suggested they would be unsure of what route to take to find them. This was a recurring theme for these women and was largely rooted in their initial negative experiences with medical professionals (as outlined in chapter five). The women acknowledged that there was a lack of trust with medical staff at times. As stated by Gill (aged 54):

“I moan to the GP – or that’s what it feels like. He seems to be the only one to listen properly. If, by chance I see a specialist there is no point moaning as they dismiss you. It is best to think of some good questions before you go in so you may then make some difference to your health. To be honest though, my healthcare is looked after by the GP mainly”.

Sometimes the women could be put on a waiting list at the hospital but the specialist they were seeing may not be familiar with the issues associated with MS. One example of this was when Doreen was in hospital with a bad chest and she had a ward visit from the consultant. He refused to acknowledge her chest infection and the possible relationship to MS and told her that it was a different area altogether. Doreen emphasised her frustration and confusion about her own experience around this:

“Oh, it was a terrible chest, tight and my ribs felt squashed. I didn’t want to go to the hospital, I wanted to stay at home and sleep it off with some medication...when the chief came to visit me I told him that I had been having a bad time with my MS, it had flared up again, and I were weak and lousy all over really. He just ignored me, he didn’t even look at me properly, and he said that it was a chest infection, nothing to do with the MS. But I know that when you get a flare up, you get more things, like infections, and I just was too weak to say anything to him...I was annoyed about it for a while afterwards, and when I was next at my GP’s I told him about it and he just looked at me, you know, like what the hell is she going on about...I don’t mean to be nasty, I like my GP, but you could shake em sometimes”.

6. Expectations of care

The care offered to a person once a serious health problem has been diagnosed can be crucial to supporting them in their life. Kaufman (1997) suggests that ‘*dilemma’s that*

patients face after a stroke are responses to medicine's limits and scope as well as being key reflections of medicine's goals and values'. Chapter 2 highlighted the current status of MS medical research and suggested that most care services derive from the knowledge that is produced in this area. Similar to what Kaufman (1997) describes with stroke services, MS services are not always in connection with the realities of the lived experience of MS. This point was highlighted in Chapters 5 and 6 with the women's experiences at the beginning of MS.

The younger women tended to expect more specialist health care for MS. In contrast, the older group of women veered towards more palliative care issues, such as home help, or pain relief to help them sleep. This became apparent when the women told their experiences of their current healthcare situation. The practise of neurology is now accompanied with MS Nurses who are specifically trained to understand and deal with patients living with MS. Not all neurologists will have a specific interest in MS and some of the younger women highlighted that they had ensured that their GP referral to a Neurologist was one that did have a good knowledge and interest in MS. The older women were not aware that such a request could be made and they assumed any specialist or neurologist would understand the full complexities of MS and any future developments. One story told by Doreen (aged 67) reflects many of the older women's perspectives:

"I only saw him (the neurologist/specialist) once and he seemed ok. I asked a couple of questions and he answered but then sent me back to the GP. It was only when I was chatting to a friend and she mentioned his name and said he was a heart specialist...i suppose how much does that matter as long as you're seeing someone high up, but like my daughter said, it's always better to have an opinion of someone who knows about something properly, trained and that in the area, and she's right, I should expect that kind of opinion for me".

Another example, provided by Iris said:

“This one time I had a visit from the social worker; it was when my daughter rang em because she thought I should be able to get support and help. And when she came, she were very young, not that I mind that, and she were dead nice lass, but I thought what the hell does she know about MS... She left me with the form, you know, about the meals help and cleaning, and I ended up throwing it...erm, what use is a long bloody form to me...no-one ever came back to see how I got on, or that, and I mean she were nice lassie, but I never heard again. And she were supposed to be just for disability, and that were her job, to see if you need help, and get you things, but no, I never saw her again. I mean, she could have left by now”.

7.2 Illustrative study – Josie’s story

Josie’s story provided an illustration of the lived experience of MS and the process of trying to obtain services to assist a person with MS to live the most comfortably. This extract below is taken from Josie’s transcript when she is talking about the pain she lived with:

Josie’s story (aged 32)

“You know, when I wake up in the morning I am so tired sometimes I want to cry. Every day I have pain. I never get any peace, you know, it’s all the time. Most mornings I take painkillers before I get out of bed otherwise I am in agony when I try to get up. I usually wait an hour in bed while they start working. It’s just constant Louise, day in day out...it’s like when you have had a filling at the dentist and you touch it with silver foil – do you know what I mean? The pain is all over my body, just everywhere, no let up anywhere. It’s in my skin, my muscles and I even have pain in my bones. Once I get up in the morning I’m usually a sleep again by one in the afternoon – just knackered”.

Josie said that when she wakes up in the morning she is tired. She is so tired ‘*she wants to cry*’. Before she gets up Josie takes the first session of her strong painkillers. She needs the painkillers because she lives with constant pain, day in and day out.

Josie described the pain as being like a constant annoying pain ‘*like when you have had a filling at the dentist and you touch it with silver foil or something*’. Josie described the pain as being all over her body, in the muscle, in the skin and reaching through to her bones. It takes Josie a full hour to wake up in the morning and she is usually exhausted again by 1 o’clock in the afternoon. Josie says her life is a battle each day although she is reluctant to feel sorry for herself or pitiful. Josie further said:

“I think that it’s tough because you don’t know where to get help. I’ve just started at the pain clinic and I am feeling optimistic about it. Pain is my difficulty. I can cope with everything else, like a limp or blurred vision, or the odd feelings you get around your body. But the pain affects everything you do. It makes everything difficult... getting up off the chair, going to the toilet, getting dressed...it’s a battle, each day is battle at the moment. But I’m hoping the nurse at the pain clinic can help me. It sounds like they can offer good support, and they try different techniques until you have a pain plan.”

When she had her last relapse Josie said that she just did not care anymore – even saying that if they had sacked her at work she would not have cared. Josie worked in a Government funded position and each time she has more than 8 days off sick from work she received a warning. Josie accepted that this is part of policy as they have assisted with her immediate needs such as supplying her with a comfortable chair and getting special pens for her to use as she has problems with her hands. Josie continued:

“It sounds awful, but I work with this man, Tom, and he has MS too. I talk to him about it, and he does get unwell, but sometimes I find myself feeling really cross with him because I think he exaggerates how ill he is. Like, he has never had an attack that has stopped him from walking, or he rarely gets bad pain, and he will moan to me about a sore eye, or numb patch, and when I’m feeling in pain, I could tell him to get a grip. He has been offered every drug possible as well, he has just started on the Copaxone (please see appendix 1 for BNF description), and I have been trying to get that for ages, and when he was diagnosed with MS he was told straight off. He hasn’t been through the struggles I have, I don’t want to say he doesn’t deserve them, but sometimes, I

look at him, and think why did he get offered the best treatments yet he still bloody moans...”.

Josie had tried just about every drug possible for MS except the current treatment plans advocated through the medical research. Josie had found these impossible to access and had been told she did not qualify for it. The rules state that you need to be having two attacks a year yet Josie says that she was having those but self-managing as she found the health services too frustrating. Josie was currently managing her life by being part of the pain clinic at the local hospital. Josie enjoyed this experience and said that it helped her health a lot.

7.3 Medical and Social Care Supports for MS

The women's narratives revealed 6 issues that were prevalent in their interviews in relation to medical and social care supports. Freeman & Thompson (2000) view service provision for people with MS as being sporadic and inconsistent which is also the emphasis of Chapter 7. Freeman and Thompson (2000) suggest that there is little data in this field and studies analysing service provision for the complex needs of MS are very few. They conducted a large scale study based on quality of life interviews and a structured questionnaire with a sample of 150 adults with MS. There highlighted that although there has been a shift of emphasis from hospital to community care, and also the recognised establishment of standards of care for MS, many people with moderate or severe disability due to MS fail to receive health and social care assistance. Their study raises important questions about the equitable allocation of resources and highlights the urgent need for a review of community services.

Another study conducted in 2001 by Somerset et al. examined the health care preferences of people living with MS. There were 318 participants who filled out a survey which focused on collecting information from people with MS so that they could feed back their own experiences. The conclusions for the study showed that people living with MS have a wide variation in their preferences for services, and in the highlighting of their unmet needs. Somerset et al. (2001) concluded that high quality information should be provided to people with MS over a range of care needs they may have.

Many of the key initiatives proposed in the white paper of 2005 attempt to address the provision of care for people living with MS. The MS Society (2005) stated:

”Very welcome, however, are the proposals to develop an integrated health and social care plan, and we eagerly await the good practice guidance in 2007. It has long been recognised that provision currently suffers from lack of integration and this move could offer a significant step towards improving the quality of these vital services”.

The biggest concern for campaign groups is the fact that there is no statutory duty for the NHS and local government to cooperate with the components set out in the white paper. The MS Society (2008) also raised key concerns about the white paper for neurological services. Some of the key points raised that are relevant here were:

- The use of advocacy for people with MS and their families is needed to help support them through the process of identifying needs and any consequent applications. Many of the women in the study highlighted their frustrations at application processes and found themselves giving up;
- There needs to be more specialist workers in the area of MS specifically including neurologists, nurses and care workers that have a multi-disciplinary

approach. Some of the women expressed confusion at services not working together and appearing too complicated to access.

Summary

During the interviews it became apparent that the women's care options were, at times, dependent on their available access to specialist treatment such as a neurological specialist unit or a clinician or neurologist in the area of MS. As highlighted in Chapter 6, many of the women had struggled with getting past the first post of GPs and once a diagnosis had been given of MS, it became important for the women to have some contact with neurologists or specialists regularly. Chapter 7 has raised some key concerns in relation to past and current service provision for women with MS. The theme of 'medical care and social care supports' identified 6 categories by the women as highlighted in table 7a. Alongside this there were secondary problems with access to care. Many of the women were very clear about the problems with accessing care but many of the older women had accepted that this was so.

Chapter 7 highlighted 6 key issues identified by the women in their interviews. The narratives have shown that the pathways of care for the women were not clearly signposted. This then had an impact on the women's lived experiences of MS.

Chapter 8

Making sense of illness

Prologue

Chapters 5 – 7 have highlighted the women's journey to experiencing MS, being diagnosed with MS, and then obtaining health and social care supports to assist them in their quality of life. Chapter 8 encapsulates the women's self understandings about the onset of their MS symptoms. These self understandings, which were created by the women, either at the time of the early symptoms, or through reflection over the years, provided a basis for the women to tell their story of MS. The theme of Chapter 8 represents how the women made sense of their MS symptoms, and how they interpreted the impact it had on their lives.

Chapter 8 precedes a further discussion about the impact MS had on the women's personal relationships and then on their coping skills for dealing with MS symptoms physically and emotionally.

Introduction

First the women's narratives around understanding the onset of their MS symptoms is highlighted. Secondly a further discussion around the social circumstances of health and further understandings of chronic illness are outlined.

Interpretation of data collection

The women interpreted the start of their MS symptoms as relating to an event of circumstance in their life. The data presented in Chapter 8 explored the women's narratives about the beginning of their MS symptoms, and examines how these become embedded in their understandings of having a chronic illness.

8.1 Linking trauma to the first symptoms of MS

Arthur Frank (1995) discusses in his book 'The Wounded Storyteller' (based on research about people with cancer) how people who experience illness, both short-term and long-term, need to make sense of what is happening to them. Frank (1995) recognises that stories of illness empower the teller in several ways. Stacey (1997) also draws on this theme in her book exploring people's experiences with cancer. Firstly, the person telling the story becomes a creator of knowledge through discussing and sharing their experiences (Koch, 1998). By doing so, they become recognised within their 'lived experience' and provide insight and common sense understanding to people in similar situations – in this instance to other women with MS (Capps, 1996; Koch, 1998). When somebody has been disempowered through an experience of illness, certain types of knowledge within and around the illness can provide empowerment (Bruner, 1987; Frank, 1995)^{vii}.

Almost all of the women linked initial symptoms of MS to an emotional experience of their life. This was a primary understanding for all the women in explaining their illness and they had each made attachments to a specific life event. (However, they had all made this link with MS symptoms and emotional trauma association over time when doing their own reflexivity on their lives). This could be because their symptoms presented at a traumatic time in their life course or it could be something significant to help them remember the time and place in which it happened? These self explanations become commonplace for understanding why certain things are happening in life. It is a belief system and is something to hold onto when the uncertainty of ill health is pushed into people's lives (Rose, 2006). Religion is often used in this comforting way. The women could also have attached life events to their ill health as a reaction to being dismissed initially by doctors and therefore offered a new understanding for the situation they found themselves in. It could also be that the women's symptoms were directly, or in part, related to the traumatic emotional event.

Grief and the beginning of MS symptoms

Some of the women associated stories of grief with the onset of their MS symptoms. Josie (aged 32) related her first attack to her mother's sudden death from cervical cancer. Josie explained that the 2 events occurred simultaneously. Josie said:

“When I had the first attack and was rushed to hospital – mainly because it was so severe - my poor dad was frantic. My mum had just died and then I was being looked at in the brain unit for brain tumours and cancers. It was a horrible time and you just wouldn't think all that would happen to one family would you? It was stressful, a very stressful, time in my life and for the rest of my family, especially my dad”.

Josie highlighted that her family had been through a tough time prior to her first symptoms – which presented as a more severe form of MS. Josie continued:

“I think my mum dying was a factor in the MS. It’s obvious really. She had been living with cervical cancer for 5 years and nobody expected her to die. It sounds daft but it was a shock to us all. She literally declined and died all in a weekend. Six weeks later I was in hospital being looked at and I couldn’t move, it was a terrible time for everybody and my dad must have been worried sick and my brother remembers him just being in a real state – I do think I would have come out in MS anyway but maybe at a later date”.

Josie explained that her mums’ sudden death contributed to the onset of her MS symptoms. Josie felt that she may have ‘got’ MS anyway at a later date; it was the family stress of her mum’s death that brought it out when it did. Josie added:

“People say to me, it’s no surprise you are ill because you have had so many things going on. I mean, people don’t understand MS, they don’t know what it is, it confuses them because of the way it is, and I think people tend to look at your life and identify things that have happened to cause the MS. Saying that though, I do think that I was switching off with my first attack, I was trying to grieve and it was horrible”.

Alison (aged 39) explained that the death of her first husband coupled together with having 2 small children preceded her first attack of MS. Like Josie, Alison’s first MS attack was severe. Alison recalled:

“It was terrible. I was grieving obviously (for her first husband) so I didn’t take too much notice of what was going on with my body. Grief is a strange thing and I have heard that it can cause physical pain. A friend of mine once told me that she physically hurt when her father died. I didn’t equate the pain in my body with ill health but with my grief, and it was a shock to collapse. But then when you are in hell, the pain hurts, and when I fell ill and I had to do something about it, it was relief”.

Alison also recognised this to be directly linked to the continuous mourning for her first husband suggesting that her illness continued out of respect for him. Alison said:

“I couldn’t say this in front of Mike (her second husband) because he is a good man. But the MS, or the pain of MS, makes me think of Paul (her first husband) and if it goes away I worry that I might forget him. The symptoms happened as

he died – it was as simple as that. He died and I got ill. Sometimes I think I might just need counselling as I obviously haven't got over the grief and it's so hard to just let go. But who could I tell all this to – they would think I was mad”.

Alison suggests that because her MS started at a vulnerable time she finds it difficult to let go – describing a feeling of deceit if she were to get better. Like Josie, Alison identifies grief as being the trigger for her first MS attack, which for both these women presented in a severe form of a first relapse of MS.

Family conflict

Family conflict was involved in several of the women's stories of trauma and the start of MS symptoms. For example Jesse (aged 26) relates her onset of MS to an emotional time she experienced with her family. Jesse had revealed she was a lesbian to her immediate family members and Jesse felt that they had responded negatively to this information. At the time of Jesse's disclosure she had just left her first long term lesbian relationship and said she was hoping for some emotional support. For Jesse the emotional pain of disclosing her sexuality and then being rejected by her parents overshadows the experiencing of MS symptoms. Jesse suggests that it was inevitable that her body would react to such trauma. Jesse was focused in making this link between her traumatic event and the beginning of her MS. Jesse became quite emotional telling this part of her story. Jesse says:

“Telling my parents I was lesbian was a big thing. I knew their views on these kinds of issues so I thought long and hard before I told them. It was a stressful time anyway (as I had just split with Lydia and that was hard) as I had decided to openly ‘come out’ instead of just being ‘myself’ with a close circle of friends. I was upset with my parent's reaction because I thought they might support me, I was hurting, and I wanted them to help me, I was naive. I must have been feeling vulnerable though because it turned out to be a mistake. Instead of getting support from my parents I was rejected by them. They could not cope with my grand declaration of being a lesbian and asked me not to tell any other

members of the family and put me on a massive guilt trip – they even suggested that it could finish off my grandmother who had been in and out of hospital. I tell you it was a tough time where I felt like no body understood me. They dismissed any feelings I had and how hard it was for me to tell them I was a lesbian...they tried to talk me out of it, suggesting it was a stage, and I needed to get a boyfriend to stop being confused. They made me feel dirty and disgusting”.

Jesse said that her early symptoms of MS started around this time. When Jesse explains this part of the story she describes that she felt hurt and betrayed by her parent’s reaction to her sexuality. Jesse also suggested that she was unsure what happened first – the symptoms of the MS or her tension with her parents. She recalled:

“I remember I wasn’t sleeping properly at the time and I certainly wasn’t eating properly. Before I started discussions with my parents (if that’s what you can call it) I started getting pins and needles in my right arm. It didn’t hurt at that point but my eyes used to get sore and painful – in fact I thought I needed glasses. When the whole thing climaxed and it was obvious I needed to move out of home my body was agitated all over. My arms and legs were tingling, my eyes were not only sore but my vision was blurry, and I started getting the most terrible pain in my arm joints. It was a dull, deep ache that came and went. It was a frightening time for me and so much was going on in my personal life. And I literally had no family support at all”.

Jesse revealed that she was experiencing intense emotional issues at the time when her MS symptoms appeared. Jesse confirmed:

“Without a doubt I got ill because of the stress. I had always been a problematic child by my parents account and this was the icing on the cake – if you know what I mean...I was stupid to keep trying to be like them, or trying to get them to understand me. It was never going to happen in the way I wanted it to. I find life easier now because I don’t have them in my life very often”.

Jesse vividly remembers her first symptoms of MS and the event is firmly established in her lifecourse. Jesse said that the pain of that time has never really left her but she has managed to learn to live with it. Jesse acknowledged that she may have

experienced mild MS symptoms for a few years previously but this recollection details her first 'attack' that impacted on her physical and emotional wellbeing. This experience of family conflict was echoed by Sammy who outlined her trauma preceding the onset of her MS symptoms. Sammy recalled:

"I have never got on with my family properly. I have 2 sisters and 2 brothers and I am in the middle. I used to wonder how I had managed to be like I am yet they are so different. I was convinced I was adopted! (laughs) When my first symptoms started I had been arguing a lot with my mum and dad. Dad was always in charge at home and he bossed my mum around like she was a child. He bossed us girls around in the same fashion but for some reason I always argued with him. This got me labelled as the troublemaker and as in lots of families they got angry with me because I didn't fit in with them. I can't put my finger on one thing that made them dislike me – just lots of things added together. I started with the bad eyes and headaches (when the arguing got really bad at home), like a migraine and I would be left with movement problems in various parts of my body... I left home at 16 after lots of rows with my dad and this coincided with my first attack...I would say the stress and trauma brought on my illness, it could have caused it, I don't know, but I know that the illness started when I couldn't cope with the stress. I sometimes wonder if it was a reaction, my body saying piss off".

Sammy described her first MS symptoms appearing when she was in a time of emotional stress and revisited this several times throughout her interview. Like Jesse, she felt that the traumatic event had encouraged the MS symptoms. Sammy suggested that she had struggled with family life since being a young girl and when she started puberty the reality of her family relationships became more obvious. Sammy said:

"When I look back I was too young to be experiencing stress. My mum and dad were not very good parents and I am convinced they would have been better off not having children. They couldn't cope with anybody being different to them and if you didn't fit in with them then there was nowhere else to go with them. I am sure that this stress brought on the MS".

Like Jesse, Sammy said that she may have experienced symptoms even earlier than the description she gives of her first remembrance of MS symptoms, but this attack was the first significant health experience for her. This was a dominant theme that

spread across most of the women's stories – the connection between trauma and the experience of MS symptoms.

Family conflict was also identified by Liz as a connection to her health problems. Liz (aged 35) recalled that MS first entered her life when her parent's marriage broke up and it came out that her dad had been assaulting her mum. Liz was 15 years old at the time and she felt extremely upset finding out this information out about her dad. Liz said:

“Gosh, I remember being a child really when I first got ‘MS’ symptoms. I know a lot of women with MS say that they can trace their symptoms back to being a child or young woman. I used to read a lot as a teenager particularly in the evening or in bed. I remember that I couldn't read a book properly as it hurt my eyes and my vision was blurry. I remember I also got sore legs and arms and muscle aches that couldn't be explained. I was going through puberty, my parents' divorce and having these odd symptoms. People just passed it off as my age and stress I mean teenage years aren't good are they?) so I never approached the doctor for a while. My mum was also distracted at the time because of things with my dad so I didn't like to burden her with more worries”.

Liz (aged 35) related the beginning of her MS to the emotional trauma of her parents splitting up. Liz also could not cope with hearing that her dad had been violent towards her mother. Liz continued:

“...well, when I first heard that dad was leaving because he had hit mum, it was a shock. I have asked myself over the years if I knew, or heard, or something, like any signs, to tell me that I knew that dad had been hitting her. I still don't know the full extent, but I know that I used to love my dad, worship him, and then, well now, I have a difficult relationship with him, because, well, he let us all down badly. I blamed my mum for a long time too, because I was confused, and because I didn't want to believe these things about him. I wanted him to be wonderful, like I thought he was, and it didn't fit in with my ideas on life. This was a really miserable time in my life, I was very down, very depressive at that point too, and the MS started. Pretty crap actually”.

Like Sammy and Jesse, Liz associated emotional trauma with the beginning of her MS symptoms. Sammy, Jesse and Liz all highlight family conflict as the trauma relating to the beginning of their MS symptoms. For example Emily (aged 42) told this story after explaining her life before her diagnosis of MS:

“I’ve always had a real funny relationship with my mum you know. She was always telling people I was lazy, and fat, and that I am always asleep. She has always been critical of me and anything I do and I sometimes think back to when I started with the symptoms and wonder if this was why. You see, my natural dad had mental health problems and when him and my mum divorced when I was a small child she used to identify things about me that were mad like him (laughs)”.

Emily had a lot of ‘*messy*’ (her term) relationships in her life before a diagnosis of MS happened. She told me that preceding her diagnosis at the age of 38 she had probably experienced MS since she was around 18 years old. She had been taking antidepressants since this time and says her mum had encouraged her to do so suggesting that she needed them and associated it with her dad’s mental health problems. Emily felt that she did experience bouts of depression but did question whether her downside was just part of her personality that her mother could never accept. Emily also felt that her mum was cruel for attaching her dad’s mental health problems onto her. Emily further explained that her mother often undermined her, and still did, although she found it easier to cope with now. Emily said:

“My mum is one of those mums who just picks. She always has done since I was young. She used to describe me as lazy and make out I couldn’t be bothered to do anything – but now having the MS explains so much, and is such a relief. I’m not mad and I’m not lazy...mum spent lots of years picking at me, pulling me down, but in a way I can’t tell you, it was done through comments, always with a smile, snidely done, she’s clever my mum...I sometimes think that she brought on the MS, I might have got it, I don’t know that, but something makes me feel that she put that on me, with the way she was, cruel to me”.

Emily continued:

“I can say hand on heart that, well I got chicken pocks at the same time, about 17, and that floored me, but it was when the tensions between me and my mum, you know the picking, telling me I was like my dad all the time, you know mental, that’s when I got all these aches and pains, I was never the same from then really. I would say I probably had a slight drink problem when I was about 20, but I managed to get through that and then next minute I was married and having children”.

Rebecca (aged 44) explained that her onset and almost immediate diagnosis prompted a traumatic time for her, significantly in her relationship with her mother. Like Emily, Rebecca had always experienced tensions in her relationship with her mother which surfaced at the time of her diagnosis. Rebecca recalled being in hospital where she had received her diagnosis of MS. Rebecca is upset as she remembers what the consultant told her when she asked for her parents. Rebecca remembered one particular argument with her mother after she had been diagnosed with MS:

“I had been home from hospital for about a week and I had been diagnosed with MS at this point. Mum had been quiet about things, not said a word about anything, and I could feel the tension. I was obviously distressed yet mum was not supporting me like she should do. Mum screamed at me that I was an embarrassment and she was ashamed that I had MS. I was so angry I punched the window between the kitchen and dining room”.

At this point Rebecca breaks down but insists she wants to continue. Rebecca said that she has never told anybody about her relationship with her mum. She said that most people think she is from a supportive family as that is what they look like from the outside. Rebecca continued:

“My dad was a military man, an Officer, and I was raised with discipline. He is a good man and I respect him enormously. Mum was (and still is) jealous of the relationship I had with dad (especially as a young child). I think this is because she is a cold woman, and because she was a cold woman to me and my sister. We were raised without love and attention from her. My sister herself has

grown into a cold woman now, but I hope I haven't. I have always tried to be warm and approachable to people because of my mum's ways".

Rebecca said the diagnosis of MS gave her a release from the emotional turmoil she had been experiencing. Rebecca said it gave her something else to think about.

Rebecca stated:

"My relationship with my dad suffered because of my mum's jealousy. I see them both now, but I find it difficult. Dad helps me when I have very bad days, such as shopping, but I try to manage myself. I have my job and some friends, and I enjoy cooking, some days I can spend the day cooking".

Alison who suggested her initial trigger for MS was preceded by her husband's death also explains that her relationship with her mum has always been marred by underlying tensions. Alison says that her mum is a perfectionist and always required high standards of her. She thinks that her mum felt let down by her as she had a promising future as a musician but got married instead of pursuing a career. Alison outlined:

"From the beginning of my MS, mum has never sympathised with me. I don't want her to fuss me, but acknowledge that I have an illness....it is quite regular for mum to ignore my symptoms or brush them away as not being real, to dismiss how I'm feeling.

Interviewer: Do you find that difficult?

A: Yes, yes, I do find that really tough, because, to a certain extent you expect, support from those around you, or some empathy. That's the thing with this disease; a lot of the symptoms are invisible or difficult to explain. You do expect your mum to support you though. I have friends with fantastic parents and I am so envious. Why can't my mum be like that? A lot of it is because I was my dad's favourite and she was jealous. My dad died just after Paul, about 6 months, and that pushed me further into a depression. Grief overloads you, but during this time my mum was rubbish with me"

This could be a common emotional reaction by a family member to illness however

Alison continued:

“.....why I am surprised puzzles me because mum has always treated me differently. I have 2 brothers and they are so bloody wonderful yet all my work goes unnoticed. I went to music school and got a first but she still puts me down. I thought when I became ill she would respond to me then. I had no support really from her even when Paul died and the children were small. I became ill almost immediately on my return to England and she dismissed my **hell** (emphasised) I was in at the time”.

Alison told me that the more ill she became the more time she had to think and reflect about her life and how it had turned out. Emily (aged 42) said that although she recognised at the time her mum was unreasonable with her, it's only the past couple of years she has wondered if the tension added to her MS. However, those who had made a connection were very sure that this was the cause, or should at least be a recognised factor in MS. For example, Rebecca (aged 46) talked about her onset of MS being linked to a traumatic childhood – she was only 18 when she was diagnosed. Rebecca suggested that she had a complicated emotional relationship with her mother and this was highlighted further with her diagnosis of MS at a young age. Rebecca said that her mother always pushed her to the side and ignored her emotional needs as a child. Both these women, like Emily, still had a relationship with their mother but found it an incredible strain. Emily commented that she kept her relationship with her mum on a practical level – such as helping out with the children and never discussed intimate issues.

During their recollections several of the older women recalled traumatic incidences that had occurred around their first symptoms. For example, Alice (aged 67) remembers her life being extremely stressful at the time of her first symptoms and Doreen (aged 69) recalls multiple stresses in her life. Many of the older women also commented that they were married and raising children describing a picture of a 'patriarchal lifestyle' when they first experienced symptoms. For example, Alice and

Doreen both said that they had been married at the time of their first symptoms and raising children in a busy environment. Both women had taken charge of looking after the home and also worked in paid employment. They both painted a picture of a 24 hour day with little or no time for themselves. For example, Alice and Doreen went on to divorce their husbands as the children got older explaining that they had experienced years of hard work and misery in their marriages.

The following table 8.1 presents each of the women's explanations for their own onset of disease, attempting to make a link between symptoms and traumatic event. This is referred to as a 'genesis narrative'.

Table 8.1 is a 'genesis narrative' of the interviewee's own link between initial symptoms and life events.

Women interviewed	Age of woman	Initial symptoms	Own Explanation
Louise	21	Sensory symptoms with no major disability	Long-term family problems that reached a peak prior to her first attack
Jesse	26	'Severe attack' which left her bed ridden for a couple of months	Break up of long-term relationship and parents response to her being a lesbian
Sammy	30	Anxiety, depression, numbness, blurred vision and balance problems	Long-term family problems with particular emphasis on arguments prior to onset
Josie	32	Severe symptoms and hospitalisation for three months. Unable to walk, speak or see clearly	Death of mother and emotional family rollercoaster for the previous five years
Liz	35	Sensory symptoms leading to painful muscle spasms	Stressful life events, particularly family stresses leading to first attack
Alison	39	Severe collapse which resulted in a month's hospitalisation	Relates to death of husband and being left with two young children
Jenna	42	Unable to walk and bad vision	Makes no link to personal events although highlights busy workload
Emily	42	Sensory symptoms, vision problems	Stressful life events and complete 'life overload'

Suzanne	45	Sensory symptoms, and particular bad back pain which she could not shift	Acknowledges stress as being a trigger but does not feel relates to one clear incident
Rebecca	46	Numbness, balance, coordination	Relates to emotional problems experienced as a young woman within her family
Gill	54	Sensory symptoms with very poor vision	Unhappy marriage and lack of control in her life
Linda	57	Chronic symptoms of painful muscle spasms and poor vision	Links directly to genetics in her family history
Doreen	66	Limp in her leg and poor co-ordination	The stress of juggling family and work commitments – says husband was unsupportive and she felt torn in two
Doris	67	Anxiety, numbness, poor vision and poor coordination	Links her worst attack to the emotional and financial stress of divorce and having to support three children.
Alice	67	Optic neurosis and bad legs	Emotionally stressful period prior to first attack
Iris	71	'Sore eyes and funny vision'	Stressful marriage but says 'you have to get something'

Most of the women had an understanding of what had caused 'their MS' on reflection. Linda and Jenna did not link their onset of MS to emotional or stressful events although Jenna did highlight that she was working a lot of hours when her symptoms began. At the onset of MS almost all the women articulated some traumatic event to coincide with their first symptoms (see table 8.1). This was always an emotional encounter related to their immediate life course. Although this could be a build up of tension located in the women's life history, in the women's lives there was one major impact that they related to the onset of disease. Many of the women had internalised these feelings for a number of years – questioning their own judgement. One of the older women Alice (aged 67) recalled:

“Getting diagnosed with MS actually gave me an ‘opt out’ from where I was at. At the time I was working so hard running one of the (families) guest houses - and I hated it. It was a twenty four hour job and it was very, very difficult. Being ill allowed me to think, be alone and assess where I was up to. That was years ago now and I haven’t looked back”.

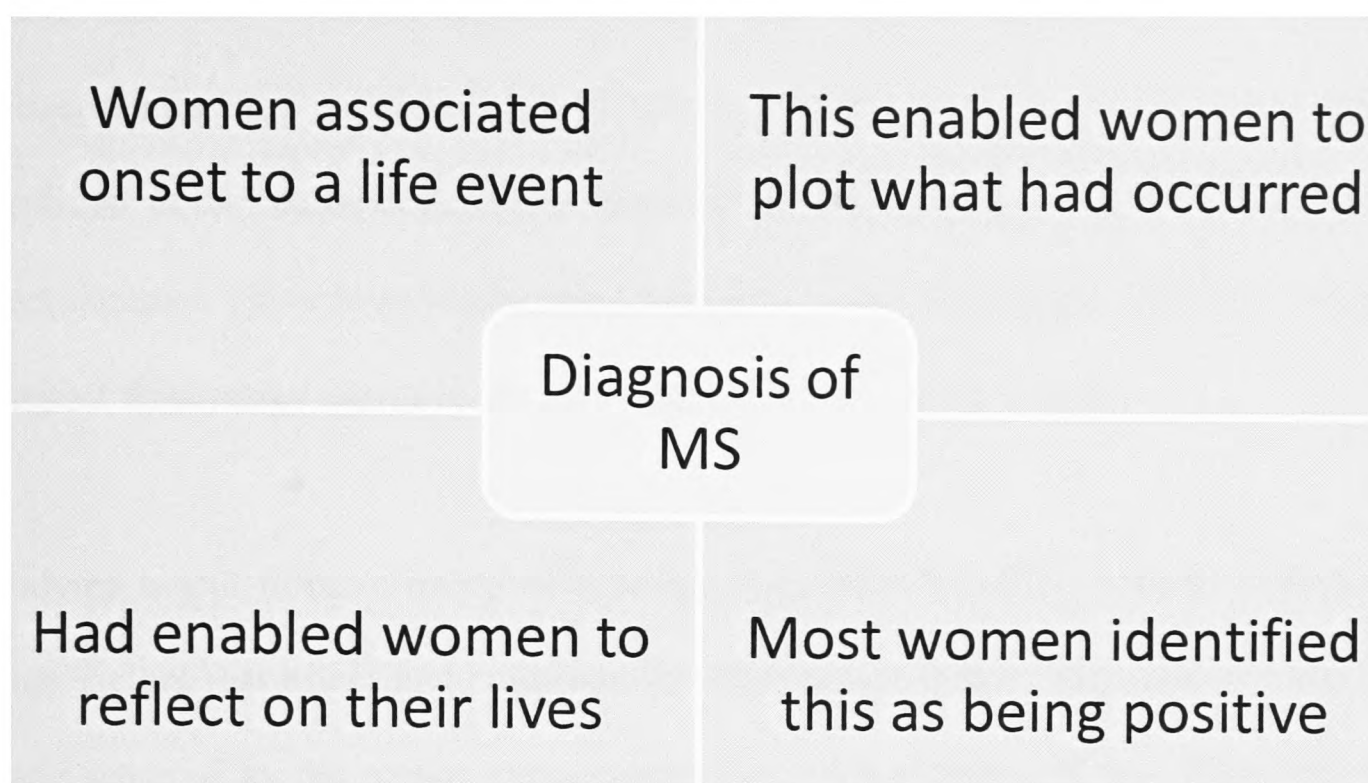
Alice accepted her MS onset to be a reflection of her lifestyle at the time. She had previously been told she had anxiety for a number of years but related this to her unhappy life situation. The diagnosis of MS meant that she could evaluate her life and remove herself from some of the situations she had found herself in. Alice (aged 67) outlined the social and emotional impact of experiencing MS and eventually getting diagnosed with MS:

“The man I was married to (Tarquin) was Asian, and it was difficult crossing the boundaries of both our lives. He came into my life with quite an extended family and he was very very obligated towards them. I always came second, always. Being a white woman it was very difficult at the time we were together to have a cross racial marriage. We did well that his family allowed the marriage and in many ways they did support our life together. But it was a controlling life for me. We had a daughter together and I didn’t want religion in her life – can you imagine me trying to tell this family of practising Muslims that their granddaughter would be going to a non religious school? On top of that I wanted my independence back, I was young when I fell I love with Tarquin but that died over the years, to the point that I wanted to leave him, and the family, but couldn’t because I didn’t know how. When I was eventually diagnosed with MS it gave me the chance to say, ‘this is serious, life is short, I have to make some changes now’”.

Alice emphasised her deep unhappiness in her life at the time of her MS diagnosis.

Alice describes the problems she had faced, and was still facing, in her marriage and relates a lot of these to the strains of a cross cultural marriage. Alice took the diagnosis as a new start for her and describes the diagnosis of MS as a wakeup call on the dilemmas of her life.

Diagram 8A outlines how some of the women made sense of MS



8.2 The social circumstances of ill health

The attachment of a traumatic event or an anomaly of key events around the onset of MS symptoms had enabled the women to place the context of their ill health within social circumstances. Lay theories of health and illness have attempted to broaden the context for people's experiences of ill health such as identifying that sometimes a person may feel sick without displaying physical indications of this (Bowling, 1997). Similarly Pill and Stott (1988) argue that a person's readiness to accept responsibility for health partly depends partly on their understanding of what caused the illness. Alison believed that her husband's death caused her MS to develop and has now attached her grieving to experiencing chronic pain. Sammy and Jesse both believed that their family conflicts had encouraged MS to develop. Josie felt that the stress of her mother's death from cervical cancer had initiated her first severe attack of MS. Several of the women felt that social circumstances had preceded their first

symptoms. Blaxter's (1983) qualitative study on women's beliefs about health and illness involved in-depth interviews with 46 working-class women. Blaxter (1988) found that the women attached health and illness experiences to specific circumstances they could link into within their lives. For example, Blaxter (1988) identified 11 key causes of disease identified from the women's interviews with the most common occurring themes being heredity causes of disease; infection being a cause of disease and agents in the environment being a cause of disease.

Studying health from an interpretive perspective offers a path to start to understand other factors that effect and contribute to the onset of disease and how this can be made sense of by the person experiencing the health problem. It was clear that the younger women combined their onset of disease to a stressful life event. The younger women made this connection yet felt it was not clear how the two worked together suggesting questions over which happens first – the predisposition to MS or the stressful event? For Jesse the stresses associated with her life, she feels, brought out the MS. Jesse believed that there was probably a predisposition to MS but it could have lay dormant for years had it not been for the stress of her family. Sammy took on a similar understanding suggesting that MS is closely related to stressful events.

Lifecourse and MS

In terms of the lifecourse associating key events with their MS illness allowed the women to think about the onset of their symptoms and have a measuring tool for when and how their experience of health problems started. For the younger women in the study this was a more immediate experience and something they may change and adapt over time – for example they may have only experienced MS symptoms for

several years and could still be coming to terms with having MS and making sense of their experiences. Interestingly the older women had had a longer time to reflect on the beginning of their symptoms and offered more of a detailed recollection of the time and place in which their health problems had started although did not necessarily challenge their experiences in the same way that the younger women did. For example the older women displayed a more contented and accepted approach to their MS and recalled traumatic events in a more concise and detailed way.

Several of the women suggested that the diagnosis of MS was a relief as they now had a label to which they could make sense of their bodies. Similar to Franks (1995) restorative narrative, some of the women felt they had a structure from which they could now work with in terms of their MS. This did not mean they felt the need to be in a disciplined regime but an acceptance that it was there if they needed it.

Summary

Chapter 8 has looked at how the women offer an alternative understanding to the beginning of MS – and a continuing contributor to their symptoms. These women had never been asked by any health professionals what they believed to be the cause of their MS. They had never been asked any questions about their healthcare and what choices they may or may not want to make. It could be argued that the women attached these life events to their onset of illness in order to create understanding for what was happening to them.

Chapter 9:

The Ripple Effect of a Diagnosis of MS

Prologue

The impact of experiencing and being diagnosed with MS was a life changing experience for the women in the study. In terms of the women's life trajectories a diagnosis of MS had impacted on their sense of self as outlined in Chapters 5 and 6 specifically (this is furthered in Chapter 11). The women's thoughts and feelings about having MS had been influenced by their previous experiences with MS symptoms as many of the women had experienced these symptoms for a number of years prior to diagnosis. On the one hand they had long adapted their lives to accommodate their symptoms, but this had been done without any support, and in many ways had been a coping mechanism for the women. As Chapter 8 outlined some of the women had found their own understandings for their experiences with MS as a way to cope with what was happening.

Chapter 9 presents the narratives which revealed the impact of living with MS had had on the women's personal relationships. Several of the women also expressed the emotional transitions and consequent personal changes they had made in the lives due to their health journey and as touched on in the previous chapters, and how being diagnosed with MS had provided them with an opportunity to reflect on their lives. The women's experiences around employment are also highlighted.

Introduction

Chapter 9 examines in more detail the impact that a diagnosis of MS had on the women's lives. Their life trajectories were discussed whilst reflecting on their personal relationships and the women discussed how their relationships had changed at the beginning of MS and then over time.

First, the effects of a diagnosis of MS on the women's personal relationships are explored. Secondly a discussion about coping with the different stages of MS symptoms is explored before a further discussion around the women and employment.

Interpretation of the data collection

The theme of the 'impact of MS' is utilised in this chapter to explore some of the women's personal relationships. These are presented using the following themes:

- Family situations – exploring some of the issues in relation to their family situations. Also exploration of the women's lives who had limited, or no, family supports;
- The impact of living with MS – exploring the impact of MS, on the women, and their personal relationships.

9.1 MS and personal relationships

All the women said that their diagnosis of MS had impacted on their family and friend relationships. Emily (aged 42) explained that when she first was diagnosed (which at the time she was having a bad relapse and was in a wheelchair) one of her friends avoided seeing her. When Emily asked the friend why she had done that, she had

replied that she hated to see her unwell. Emily had never seen this friend since and felt sad that this had occurred. Emily (aged 42) said:

“People avoided me; people I thought were friends didn’t know what to say to me. They say sorry and offer support, but then they’re gone, kapusch, never to return. Kate, a supposedly good friend of mine, stopped coming to see me once I had been diagnosed with MS. I asked her why (I called her up because I needed friends) and she apologised and said she found it difficult and didn’t know what to say to me. She said she would start up again, coming round for a brew like she used to, but I have never seen her since”.

Emily highlighted, like others in the study, that the diagnosis of MS brought changes to her personal relationships. Emily outlined that initially she had gained a lot of support from her family:

“No, I would use them a lot but not all the time (in reference to her family at the beginning of her MS). Again I have the confidence now to live my MS, but back then I didn’t and that’s why I stayed disabled longer. The crutches give me the confidence to walk and that’s how I’ve been for 4 years. Now, the positive things that came out of this for me, after such a negative start, was that I took over from Linda the support officer for people with MS at the Newark NW branch”.

Emily recognised the changes she had gone through since her diagnosis of MS. Emily also outlined a change around her relationships with men. Emily told me the following story in relation to her current relationship which she explained was with a married man:

“I think he could be my one chance and he thinks his wife is having an affair and I think he’s hoping she will leave him, then it takes his decision away. But, you know, I could spend time with him, but you know maybe, maybe not, but in this past year he has given me back that confidence that I had lost, the thing is the day after I was diagnosed I went out and brought back this lad, I’d known him since school so he wasn’t a stranger, and I had sex with him. I needed to feel, you know like I had a sexuality I suppose, so we became, excuse the expression but casual sex friends, buddies whatever you like. This went on for a

while and I started to cotton on to the fact that he just came round for sex with me, whilst still taking out other women. I obviously wasn't worthy of that, and my self esteem, I was really overweight then, and my confidence were shattered, and Chris, the man I'm seeing now, has given me that back".

Emily expressed how a diagnosis of MS impacted on her self esteem and her sexuality. She said '*I needed to feel like I had a sexuality*' when re telling of her reaction of her diagnosis to MS was to have a one night stand.

Liz (aged 35) had RRMS and managed her symptoms through diet and exercise such as yoga and swimming. Liz was generally positive about her close relationships and said her husband (she was married before her diagnosis of MS at the age of 31) had been supportive towards her although he did find it difficult at times. Liz explained that a diagnosis of MS did significantly change the direction of their relationship. Liz said:

"We had discussed having children but when we got the diagnosis of MS John (her husband) was worried about the responsibility. I could be ill and we would have a baby as well. It's a double burden for him so we, or mostly he, decided not to have a family... I feel sad about that, but I accepted that this was to be my life now, without children, but it does bother me at times, but I have nieces and nephews who I put a lot of time into, and that helps with not having my own children. I see them as my children in a way, but honestly it's not the same, but, I think, I see it as compensation, I can't be a good mother but I can be a good aunt, that kind of way".

Liz also highlighted that John found dealing with her attacks difficult and upsetting. Liz said this was due to him feeling helpless and angry that her life could be limited.

"John finds it hard, and he does support me, but he is unhappy that I have MS. I can see it in his eyes. We planned to have children once, but John doesn't want the responsibility with me having MS, in case I get bedridden and he is stuck. He is right of course but I feel that I have ruined his life. I often wonder if he feels short changed cheated, to marry me when I didn't know it was MS".

On top of this Liz recognised that some members of her close family were frightened by MS. Liz said she found it easier to isolate herself with John and they were both particular about who they let into their private lives. Liz said:

“We keep ourselves to ourselves now. It’s self-protection because not everybody understands MS. It is difficult because there are good days and there are bad days. My family don’t understand that properly and many of the symptoms are personal and I don’t always want to share them with other people. It is difficult to live with at times”

Here Liz is displaying a common theme amongst the women which was one of facing the reality of living with a chronic illness. Liz explained that many of her family could not always get their heads round her MS symptoms because for a lot of the time they were not always visible symptoms. Liz said that this changed the way she discussed her health problems with her family as she felt they did not really understand what was happening to her. Liz further outlined:

“Let me give you an example of the insensitive comments I have had from my family. My mum asked John, and suggested to him, whether he seriously could have children with me, now that MS had surfaced. This was at a time when I had spoken to my mum about the trauma that John was going through and how he was doubtful, at this point, about having children (I mean now he is a definite no children man) but there was a time when maybe, just maybe he could have been persuaded so to speak. I have always wanted children, always, since I was a small girl, and my mum encouraged him to think that MS really was the end of the world. Don’t take me wrong – it is, but I look and see other women have children and they have problems, why can’t I? Why, do I have the most negative family? John isn’t, he worries for me and you can understand that, and I suppose I can’t take the risk of children when he feels like that. But my mum could have helped shape it better I feel”.

Liz explained that she felt let down by her mother when she received her diagnosis of MS. Liz believed that her mother could have offered more positive support, especially when talking to Liz’s husband, about the future and about starting a

family. However, Liz recognised that being diagnosed with MS had provided her with the opportunity to reflect on all aspects of her life:

“I probably sound like I’m moaning about everything, but I’m not really, I think I am aware of things more now, and that’s my MS that has given me that...in a sense being diagnosed with a chronic illness, jolts you awake, you have to start reviewing your life, and, hmm, how can I put this? It changes everything you thought of as being real, you question everything around you, not straight away, but over time, as new challenges come up, and often when you’re unwell you have time to think things through...for me, having MS, although difficult at times, it has made me have more depth in my life, and I would love kids, I’d be lying if I said I didn’t, but me and John have become closer, we can talk about anything now, MS does that it throws up so much, I remember just the other week John realised that I had a slight limp, and he said he thought that if I did get pregnant would it be tough on me, would it make my leg worse, and he said he didn’t want me to have to live with pain, which was kind of him to say I think.”

Liz showed an awareness of growth through her diagnosis of MS. Similar to Barrett (1995) associating the journey of MS to being a rite of passage, Liz identified that being diagnosed with MS encouraged her to re think about her life.

Josie (aged 32) had good relationships (her emphasis) with her close family especially her dad and brother who had been hugely supportive towards her. When she had been left by her first husband after her diagnosis Josie had found life difficult and they had both been ‘emotional rocks’ to her. Josie had since found a new partner and had 2 small children and her dad and brother were both practically and emotionally supportive to her. Josie and her partner would like more children but as her health was in decline Josie was unsure if she could cope with another child. Josie reflected on her situation:

“Daniel is great with me and the kids. He never judges me or anything and he is just dead supportive. When I’m bad he just lets me get on with it, doesn’t fuss me, but is there for a cuddle if I need one, he’s a good guy, I’m dead lucky. I had been diagnosed with MS when I met him and he was always fine, he never

really asked me too many questions and just accepted it when I was crawling round the floor in agony! And since we've had Harry and Simon he is fantastic. He does a full day's work then comes home and starts again, especially if I'm having a bad attack, he is a good laugh. I mean, you need humour with MS, don't you? ...with my dad I'm different because he gets upset knowing that I'm struggling with my health so I try to hide it from him the best I can, it's tough for him to take, it's a shame, yeah so I do hide my symptoms at times".

Josie, like Liz, suggested that she hid her symptoms from her family as she knew they were upset by them. She said that her partner Daniel understands her MS although she secretly worries that she sometimes holds him back. For example, Josie explained that on occasions they may be preparing to go out and then her symptoms may kick in and they will have to stay at home. The randomness of the symptoms made Josie feel confused and full of despair. Josie had a strong network of friends who she discussed her MS with and she is more comfortable with this as they are more removed than her family. Josie highlighted this:

"We like to go out for a few drinks whenever we can, and sometimes, I will be getting ready, nice new outfit, the lot, you know, and then it will hit me and I think to myself 'there is no way I am going to get out that door tonight'. Times like that effect me because I like going out, and Daniel likes going out, and I can see that is disappointing to him as well".

Josie reflected on the randomness and unpredictable nature of MS symptoms.

Throughout Chapters 5-12 the above point by Josie is reiterated as one of the key issues for the women in this study.

9.2 Experiences of the women who have few support networks

Louise (aged 21), Sammy (aged 30) and Jesse (aged 26) were the youngest women interviewed. These 3 women had previous problems with close family relationships and currently had no particular support networks around them. Louise's family found her diagnosis of MS hard to understand and they currently all ignored it, even her

sister who was a nurse (the same occupation as Louise) won't accept her illness.

Louise said:

“I tend to rely on a couple of close friends for support, for personal support. My mum was supportive at first, ah, I mean, she works at the surgery, and she was behind me in finding out what was wrong with me. But since I have had the diagnosis I feel she has withdrawn from me, hmm, not obviously, she just rarely contacts me to see how I am erm, oh, erm, I don't communicate at the moment with any of my family as they have decided to just ignore the diagnosis of MS.(that annoys me) My sister who trained as a nurse as well has avoided me, which annoys me the most especially because she should be more understanding and supportive because of her job. What sort of nurse is she? ...I need to sort my own head out about it all and to be honest I'm pissed off with them, for not being there when they should be”.

Louise said she found it easier to move away from her family as they made her feel worse about her MS because of the lack of support. Louise had a career as a nurse and had a good group of friends who she relied on. Louise was single but would like to find a partner and have children.

Sammy was a single parent with 3 children. She had no close relationships with her family and rarely saw them. Sammy coped with her MS alone with the exception of a few friends who she talked with. Sammy said:

“There's a part of me that enjoys pretending I haven't got the diagnosis yet, that I'm free still with nothing to worry about...I would still like to meet a new partner, and settle down, but I do sometimes think, not only am I a single mum, but I have MS too, and that's a lot of baggage with me now.”

All of the younger women were generally more confident and challenging in their approach to MS particularly in relation to medicine. In their private lives they dealt with their MS alone. Although Josie and Liz had immediate family support they both recognised that it was difficult to discuss their MS openly as they are fearful of

creating more concern and worry. Louise, Sammy and Jesse were very much alone in their private lives with very little support. They all highlighted that they had some good friends to talk to but on a day to day basis they coped with their symptoms and feelings alone. However, these women found strength in their isolation from their families and presented themselves as confident, challenging and knowledgeable.

Jenna (aged 42) was cared for full-time by her husband. Her relationship with him had changed dramatically as prior to her diagnosis she was a career women in a high paid job. Jenna found her changing relationship a struggle and as she was disabled to care for herself she has to rely on her husband. She said she can tell that he finds it difficult but they never discuss the tensions between them. Jenna says that becoming disabled changed the dynamics of the relationship and the first thing to disappear was the sexual and intimate aspect of it. Jenna feels guilty that they are both young still and that side of the relationship is gone – she feels her husband is disappointed. She had good relationships with wider family who she enjoys spending time with. Jenna said without their visits to her life would be lonely. Recently Jenna had employed a carer at home who has taken over the majority of her husband's care tasks for her. She said this has improved their relationship and he gets to have more free time.

Jenna explained the impact of being disabled on her marriage:

“Bob and me, well we changed when the MS made me dependent. Erm, well, he became my carer (pause) he does most things for me, well he did everything for me until we got Lydia, you met her when you arrived, she's great and she asks me what I want, she, you know, treats me like I can still make decisions. With Bob, he used to tell me, I mean that's men isn't it? **Laughs.** Bob has always been the main decision maker, for money, cars, that kind of everyday living. When I worked, and before I got the MS I have now, I didn't mind those things about him. I suppose I liked him to take charge. But now, erm, now I am disabled, it's different, because, I'm not attractive anymore, not in the way I want to be. Erm, yeah, erm, I think that I don't feel like I am a proper woman,

and I don't think I will ever get used to living in this body and being a proper woman. Me and Bob don't do what we used to do, what I'm saying is we don't make love like we used to do, I want to be close with him, but he switches off, I know I will find it difficult to talk to him. The thing that's been great about Lydia is having her to confide in, because, well I talked to her, erm, about how I was feeling about those things, being close to Bob, and she helps me to try and change things".

Gill (aged 54) was divorced as her husband left her when she was diagnosed with MS.

Gill viewed this as a positive aspect in her life and cherishes the fact that she does not have to consider anybody else on a daily basis. She had close family members who supported her with her MS and feels it has strengthened her relationships. Another positive woman about MS is Linda (aged 57). Linda has a supportive husband and children and says that MS has encouraged them all to grab life and fill it with exciting new things. Linda's husband helps care for her on a daily basis although still manages to work part-time. They both discussed how the relationship had changed for the better and had become more intimate and loving with MS. Linda said:

"It is a shock when you get diagnosed with something that is currently incurable. You worry that everything will change but my marriage has become even stronger. It was before but now it is fantastic. We do so much and appreciate one another. We never take things in life for granted – and that gives us a great perspective".

For many of the women, MS had impacted on their personal relationships and they were able to identify when and how. Employment was also another area which had been impacted on through MS, and this will now be further discussed.

Employment

Many of the women worked either paid or unpaid and this was an important aspect of their lives. For Rebecca, her career was important to her and she was regarded by

colleagues as an important and crucial member of her team. Rebecca had recently changed her hours from full-time to part-time although she justified this with having more time at home to cook– which she enjoyed. Rebecca commented:

“The thought of not being able to work in the future terrifies me as it is my main purpose of everyday living. I have changed my hours to part time, mainly because I was getting so tired – and I don’t need the money – so I thought why make life more difficult? I plan to continue working for as long as possible, hopefully until retirement. That’s important to me”.

Rebecca lived in a salubrious inner London area and said that she had no financial worries. Work was a focus for her and it gave her a purpose for the week. Rebecca said that without work she would have an empty life. Rebecca continued:

“I have ambitions still. I want to carry on working and I want to maintain my independence. That’s important to me. I like making an effort with myself and making time for friends. Realistically I do not believe a cure for MS will be found in my lifetime, or if it is I will be too old and disabled to benefit from it. My main hope is to keep my health under control and steady – like I am now”.

Rebecca enjoyed dressing up and wearing smart clothes. She felt it was important for her to keep looking attractive. Rebecca enjoyed spending time in social situations and said she wanted to do this more in the future. She was currently getting in touch with old friends and acquaintances to improve her social life. Rebecca said:

“I made a pact with myself at the start of the year to get out more and link up with friends, old and new. It’s been slow up until now, but I am doing it, I get out in the evening at least once a week, and I always treat myself to a new skirt, blouse, or dress, I love clothes, and I love dressing up.”

For Suzanne and Jenna their work experiences were slightly less positive although both felt that it was important to continue working whatever the work was. Suzanne said:

“I like work but people don’t understand MS – you know the ones I work directly with. Sometimes I feel that they think I’m being lazy if I take a break – or ask for an extra break, and sometimes I think they are deliberately awkward. Because the MS is so up and down and people don’t understand what it’s about I think they talk about me. I don’t have any real friends at work. But I still want

to go because it gets me up and out in the morning. I do fewer hours now. I've gone from full time to 12 hours a week in the space of five years".

Suzanne highlighted the decline in her working hours and how this has happened over a five year period. Dyck et al. (2000) conducted a study on women with MS and their workplace experiences, focusing on the social and institutional aspects of the work environment. The results of this study showed that with a good supportive work environment women can continue to be employed despite a diagnosis of MS. This worked particularly well if the women had positive relationships and support, and also encouragement for maintaining employment at home. Dyck et al. (2000) also stated that this is dependent on the type of MS the women live with and how it impinges on their ability to carry out their employment. It was also suggested by the authors that sometimes employers cannot tolerate the insecurity of a chronic illness like MS. Josie, who works for her local government, told me that 3 years ago she was managing 15 staff in a busy office and she was now doing lone desk work dealing with enquiries from the public. Josie said that although her wages have stayed the same her job status is different to what she used to do. Josie said that she used to be ambitious but now she concentrates on getting through each day and accepted that it may be logical for her management to do this as she was unreliable. Another story by Jenna highlighted a similar loss of status at work. Jenna said:

"When I got diagnosed with MS I was in a management training programme and doing well. When I told the manager I had MS she was very nice with me but then I just didn't progress with the training. The hours got longer and I couldn't manage to do them. In the end I asked to be put back down a grade – and I think they were relieved. It does put them in a difficult situation and I'm glad I'm not doing management because I would have had to leave eventually anyway. So I would have wasted my time and the efforts of the people who trained me".

Jenna expressed remorse at having to leave her career because she enjoyed it and liked the challenge. She commented that she wasn't prepared for the other challenge of living with MS. Jenna continued with her current work interests:

“Now I write the newsletter for the local MS society branch. I enjoy it and it keeps me thinking. My hands have been quite bad lately though and Bob (her husband) has had to do write it up for me. I would like to carry on doing this for as long as possible because it keeps me in touch with people – and I do have a good laugh. Have you seen the jokes section? Here have a look (giggles)”.

Emily (aged 42) had not worked in paid employment for more than 4 years at the time of the interview. She was on benefits and resented this although worked in the voluntary sector with people with MS. Her job when she was diagnosed with MS was with the local council working in care services. They offered her medical retirement and she took it because she had a mortgage and needed the financial security. Emily said that she didn't want to leave but her options were limited. If she had stayed and had another MS attack her sick pay could have run out and she would not have been able to afford to run her house. She had 2 children to support and felt she could not take a chance so she left. Emily outlined:

“The other job I had stairs to climb and I couldn't do it. But I don't blame the employers cause they were good with me and they offered me the choice of retirement which I had to do otherwise I could have lost my house and everything. At the time I felt like I'd took the coward's way out but I am ok with it now. I would love to work but because of my finances I manage well on benefits, sick pay and things and I manage to afford the mortgage and because of my health I can't really change that because if it all went wrong again I have no savings now”.

The women's stories have reflected how the uncertain nature of MS has impacted on their employment experiences. However, the women's experiences of employment here have shown that to continue to work, in either a paid or unpaid capacity is important for the women's sense of identity.

Summary

Chapter 9 explored some of the women's real life issues specifically in relation to their family relationships. The women highlighted how a diagnosis of MS impacted on their personal relationships but this was mainly portrayed as a positive development. The second half of the chapter detailed several of the women's employment experiences. Furthermore, Chapter 9 highlighted the changing nature that occurs in personal relationships with the reality of living with MS. The boundaries of understanding the changes that physically and emotionally occur due to the progression of MS have been emphasised and will be further explored in the next chapter.

Chapter 10:

Changing bodies and maintaining a sense of self

Prologue

The empirical findings in Chapters 5 – 9 have presented the women's experiences on the journey of facing symptoms and being diagnosed with MS; explored their health needs and how the women felt these were being met; and Chapter 9 explored the women's personal relationships. Chapter 10 explores how the women coped with the changing boundaries of their bodies when experiencing the physical symptoms of MS. Chapter 10 identifies the processes that occurred for the women from experiencing an attack of MS symptoms, then waiting to observe the symptoms settling, and then adjusting to a new situation with their bodily experiences.

Introduction

First a discussion around the women's awareness of their changing bodies through the experience of MS symptoms. Secondly, there is a discussion around understanding the bodily boundaries and how these are re negotiated through the physical symptoms of MS.

Interpretation of the data collection

As many of the women had experienced MS for many years, they had adjusted and become accustomed to managing the physical and emotional symptoms of MS. The data presented in Chapter 9 represents the stages experienced and recognised by the women during the interviews.

10.1 The changing body

“It took me a good deal of time until I accepted that my old body was gone, the young Alice, the girl who could run around (laughs), the body of her wasn't coming back in a hurry! For such a long time I hoped it would, more for the energy, but then over time, I adapted, I became used to the new me, and now, well now I tend to celebrate the new me, through my paintings, and drawings, which I can still do, I just change the way I do them now...as an artist I adapted...I don't know if I would describe myself as disabled, I actually don't like that word, it sounds like such a negative image, so I find the idea of being looked at that way by others difficult, but I accept my body works in a different and unpredictable way now, so although that's uncertain, there's a steadiness in that, do you see?” (Alice aged 67)

The above quote by Alice reflected the process of adaption that was engrained in many of the women's stories. Many of the women showed obvious signs of physical disability, such as a walking stick, wheelchair, or an obvious problem with gait or coordination. Also, several of the women suggested that one day they could be using a walking aid and the next they could be walking fine. The unpredictable natures of

MS symptoms were highlighted throughout all the interviews (Miller, 1997; Jelinek, 2010). Alice responded to what she perceived as bodily limitations by expressing them through her artwork.

“Louise, these are my paintings of hands, they are handprints, my handprints, green the colour of love, and these blue ones for healing. I had the idea because it is difficult for me to paint in the way I used to as my co-ordination isn't as it used to be, so I thought, hey, the hands are causing me problems, so I will make handprints as my paintings, these are my actual hands, so I still used them, just in a different way and without the brush!”

Alice shows through her art how she has adapted (or continues to embrace changes) to her MS symptoms and also how important it is for her to be able to still have art in her life. Similar to Boeije et al. (2002) who regarded ‘salient aspects of self’ as being important once MS is more constant in a person’s life Alice identifies art as being part of her ‘core’ as a woman. Alice further explained:

“I have always been an artist, in the way, it is what I am, it’s the way I feel the world, it just is me, and to not be able to do art again, that would be worse than having MS, MS isn’t the worse thing that you can have, and although it is tough, it was worse before, in the marriage, living the old life, now I feel free, and if having MS is part of that then I’m smiling.”

Alice’s narrative also identifies hope which was a prevalent feature in all the women’s stories. Even though Alice recognises that her physical body has presented limits to her she has found a way to re negotiate the boundaries through adaptation. Alice expressed this through changing the way she conducts her art.

Sammy identified that having MS, and the physical changes that occur, had enabled her to examine her thought patterns. For example, Sammy details this in the following extract:

Interviewer: How have the physical symptoms impacted on you then? (Sammy had been talking about the emotional aspects of MS)

Sammy: "Because I have Relapsing Remitting MS, (is that what you have too? You must as you look fine...laughs) then, well, the physical symptoms are, well I would say I have a pattern to them, but not really, I have a general group of symptoms that I get regularly then I suppose new things pop up in that, that's how I keep a handle on everything, but then the knock on effect of me trying to be controlling about the symptoms, and what I get actually pushes me to submit, in the sense that I have no idea what will happen next, and in that aspect of MS, it is good for me, although it doesn't feel like it if I'm going through a stage where I'm quite scared, but afterwards, maybe a few days I feel like I've stretched myself, it's weird to explain, it feels like I know myself better, a stronger sense of me..."

Sammy, like Alice, identifies that experiencing MS, and how she responds to the physical symptoms, has had a positive effect on her sense of self. Sammy links the feeling of being scared of the symptoms she is experiencing to her coming out of that feeling and into a positive place.

The concept of physical disability for the women, and their self-defined interpretations of how they saw themselves in many ways were similar. This was because the women expressed having to concede with the uncertainty of MS symptoms. Linda encapsulated this feeling in the following narrative:

"I am proud of myself for keeping on with it, getting up each day and embracing the new. You have to; you have to, what else would you do? Once the shock has worn off, I mean, people think I stride through all this, and sometimes I can't (laughs - sorry for the bad joke!), seriously though, by far the difficulties lie in the unpredictability of the symptoms, although, that said, there does come a point where you are used to the symptoms, and the fear goes, it's definitely the fear, that halts you, keeps you down, but once you have conquered that stage, then you start to accept yourself...I would say I'm settled now with my body and knowing that I have limitations, I think I accept them, my husband would probably tell you different (laughs) but joking away, I don't believe I am bitter".

Linda related the unpredictability of MS symptoms to feeling fear and she comprehended that the relationship between MS symptoms and fear keeps a person suspended. Linda, like all the women, also used humour as a coping strategy for this uncertainty. Linda further reflected on the uncertain nature of MS symptoms:

“Way back when I first started with the MS, that’s the most frightening time as you don’t know what’s going on with your body, and you’re not used to the symptoms, or the way your own MS is, but over time that improves I think, you stop being as frightened by the symptoms as they become more regular, they feel less intimidating. This is one of the issues I talk about at the university, when I am asked to talk about my experiences with MS...and I always say the same thing, that when you’re dealing with a person with MS you need to understand that they’re going through a process, they are adjusting to symptoms, to understanding what’s going on with their bodies...and sometimes seeing a doctor is not the right person to see...this is where I really push for the MS Nurse being available to everyone with MS and that’s how I’d imagine the future for people with MS”.

Linda recognised the important role of the MS nurse, and how the role is important for the future of MS services. Linda further noted in relation to MS symptoms:

“...and I think that as you grow with the MS, and you adapt more to the changes that happen, you gain something from all of that, whether it’s strength, or awareness, or comfort even, there have been times where I have felt comforted by my own acceptance of the MS...I think these messages are good for newly diagnosed people to hear...”

Alice, Sammy and Linda all highlight a similar process where they identify their own personal growth through MS. In this next section the adjustment process is further explored in relation to physical disability.

Physical disability

Almost all of the women had used a walking stick or wheelchair at some point as a result of MS and had found this adjustment difficult. Boeije et al. (2002) conducted a study around the downward phase of people with MS and concluded that the adjustment period to physical decline was a different process to negotiate. Boeije stated (2002: 886):

With the loss of physical faculties and performance patients cannot carry out all the tasks they once considered worthwhile and took for granted in their lives. As such, these losses pose serious biographical risks...now they have to be cared for and have lost a great deal of their independence.

One recollection from Emily showed that the need and use of aided equipment was a significant event when it first occurred. Emily said:

“I was having a ‘big’ relapse when I got my diagnosis of MS and I couldn’t get about on my own. My family helped me to get the house organised – literally in one day they came and moved everything downstairs. My bed, I already had a bathroom downstairs, and they made everything accessible for me. My family are really practical people but I was devastated. I cried and cried and couldn’t get my head round it”.

Emily recognised that a change had occurred in her immediate environment and this added to her distress when she had just been diagnosed with MS. At this point Emily believed that everything in her life had changed and she found it hard to comprehend.

Emily continued:

“My legs at the time weren’t working – they were numb and felt like they weren’t there - and I used to stay in bed thinking that because I couldn’t feel them I couldn’t use them. This would make me cry and feel sorry for myself. I have since discovered though that I can use my legs. I have never had complete feeling come back in them so it was either stay in bed or get myself a stick or chair to help me get about. I have got used to my legs now. If it is dark or my eyes are closed it feels like they aren’t there, but if I can see what I’m doing I can use them”.

Emily highlighted her transition from imagining that she was incapacitated to re negotiating her bodily boundaries. Over time she had discovered that it was a matter of adjusting rather than assuming her body (as she knew it) was completely gone.

Boeje et al. (2002) draw on the concept of ‘identity reconstitution’ to understand the process of adaption that takes place, or the renegotiation of boundaries in relation to the self. Boeje et al. (2002) highlighted that by developing and sustaining aspects of self difficulties can be overcome. Emily’s narrative reflects the overcoming of her physical disability when she noted *‘I have since discovered though that I can use my legs...I have got used to my legs now’*. Like Alice’s earlier narrative and her use of her

hands in her artwork, Emily has recognised that her legs can still be used, just differently to how she had previously experienced them.

Kaufman (1997) raised this issue of changing boundaries in her study of patients who have suffered a stroke. Kaufman discusses the disruption to the body and boundaries in which it was, and now is, experienced:

Stroke-the various pathological processes resulting from disruption in cerebral blood flow-lends itself to a phenomenological investigation of the nature and ambiguities of boundaries for three reasons. First, stroke is an assault on the taken for granted body-the 'natural' 'right' sense of self. Though a stroke is a specific physiological event, the resulting impairments may be diverse and profound, involving physical, cognitive, sensory, emotional and/or motor functions...In short, stroke is a condition in which many accepted boundaries must be re-evaluated (pg 341)

Kaufman (1997) recognised that the process from which a stroke occurs, and the impact on the person experiencing the physical reaction, requires a renegotiation of what the bodily boundaries are. A similar understanding could be applied to people experiencing MS. An event occurred which involved an attack within the autoimmune system which in turn disrupted the flow of the central nervous system (CNS). The person is left with physical impairments that ranges, or includes, all functions of the body. This could be called the 'shock stage'.

Secondly, Kaufman talked about stroke rehabilitation suggesting that because there is no cure for stroke there is no authority on long-term care principles. Similarly, MS treatment resides in this lost space, again a qualification as Kaufman puts it to discuss the boundaries of the situation. This could be called the 'disorientated stage'.

Thirdly, Kaufman said that the prognosis of stroke is uncertain with nobody being able to precisely determine which impairments will disappear or if they will disappear. The MS prognosis of uncertainty can lend itself to the one outlined by Kaufman and this stage could be called the ‘reconciliation stage’.

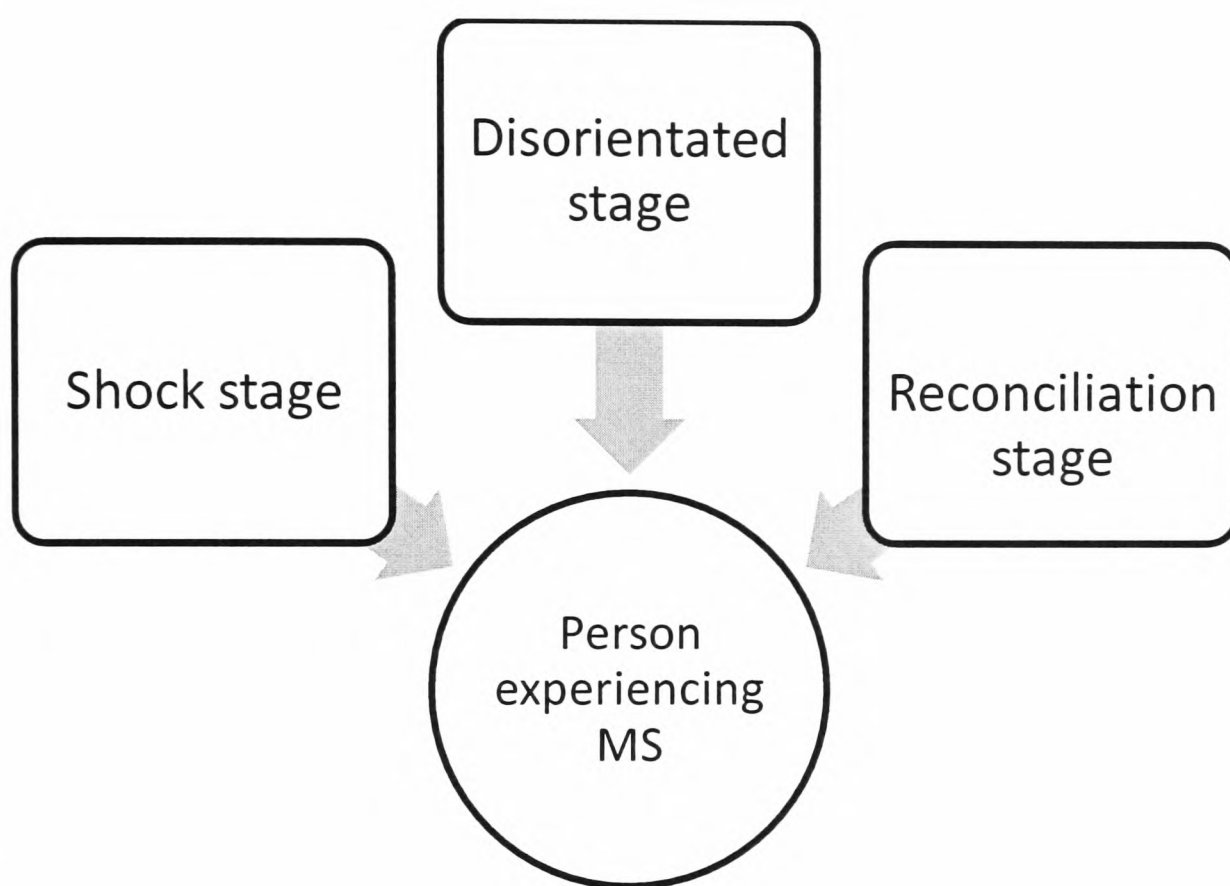


Figure 10A: 3 stage approach to experiencing the physical symptoms of MS

Lifecourse disruptions

Figure 10A can be applied to some of the women’s experiences to gain some understanding about the process of changing boundaries for people with MS, and can be further developed to identify the lifecourse disruptions which were also expressed by the women during their interviews.

For example, the women who had experienced MS for a longer period had dealt with the disruptions to their lives over a number of years. This was a complex process

because firstly the women had adjusted to experiencing MS whilst not having a tangible understanding of what was happening to them; secondly a diagnosis of MS had triggered a plethora of adjustments both physically and emotionally; and thirdly time and distance from their experiences had created new adjustments for the women.

The time scale between the disruption and gaining an understanding of what had happened was a number of years. This gave some of the women a delayed reaction to the disruption – or they thought of the disruption as not being directly associated with MS but with other factors in their lives. As Chapter's 5-9 outlined many of the women had formed their own opinions on what was happening to them when they experienced MS. They needed to do this to give an understanding to the social context of their experiences and to also give them some clarity so they could get on with life.

This is best explained looking at the story of Doris (aged 69):

“I had to make sense of what was happening and I knew I wasn't just depressed. You know sometimes don't you – deep down you know what's what. But I had kids and a husband and I had to carry on. I didn't have to time to be confused. I was worried but I just kept it to myself. I knew that something was wrong and I just put it down to life and being busy. I worked round the symptoms when they happened – like if I got a funny arm or a bad leg I would just think I was run down or make sure I was eating properly”.

Doris talked about her life disruption as being associated to her lifestyle even though she knew that there was something wrong with her health – she says '*deep down you know what's what*'. Doris said that she had to find a coping mechanism because she was gaining no assurances from her doctor or anybody else around her. ^{viii} Making sense of the symptoms in this way was a common thread in the women's stories.

Gill (aged 54) recounted a story from the 25 year period she lived with symptoms to diagnosis of MS:

“One time I had an extremely, sore, painful leg, which had been pulling, or I’d been pulling, you know that feeling of heaviness, where you feel like your pulling parts of your body with you, I suppose that shows you still have the strength, it’s a bit like you’re holding yourself together, just about anyway, (laughs) oh what would we do without humour! Well this had been an ongoing symptom of MS, but obviously I didn’t know that, and I’d been fobbed off, like I told you before, and then I remember just having this moment, it was like dadah! I was dealing with it, I really was accepting that these things were happening, and I was still getting on with life, I didn’t even feel too stressed by the symptoms anymore, as I think at this point I had them on and off for about 10 years, and if I was going to die I suppose I would’ve gone, so it was like, yeah, ok, you’re alive Gill, and you know, I suppose I could class myself as being adaptable now!”.

Gill recognised that she had adapted to her MS symptoms even before her diagnosis and that she had accepted her changing body, mainly because she had had to. Gill further explained:

“I suppose when the diagnosis came, yeah you have shock, a sense of loss all that you know that goes with a diagnosis of anything, whatever it is, but then I evaluated where I was, how I felt about it, and I realised that I’d been living with this, dealing with the symptoms, for a long time, a lot of years, never knowing when the head would be reared so to speak, no control over the illness, yet I had, because I had survived, I was here, today, living and breathing, and something clicked in me, and I felt peaceful, just calm about the whole things, nearly like I could hang the gloves up, the fights over, relax now...and that helped me a lot, and stayed with me too”.

Gill further outlined:

“The body’s funny in the sense that you don’t realise how much of a body you are till it stops working, and I mean that in a positive way, as I gained so much from that, not seeing myself just as what I look like to others, I mean, come on, dragging legs around and walking into things, you wouldn’t want to be getting too precious about the image of yourself. (laughs) moving around and about takes courage when you have to deal with a body you’re not sure of, and this was always worse before the diagnosis, way back at the start of symptoms, that period was more disruptive to me than anything else, really bad time, but by the time I was diagnosed, then how I feel today, I trust myself and my body now, even though I don’t always know what’s coming up, I adapt easier I suppose”.

Gill highlighted a process of acceptance, similar to Emily that she had gone through over many years. Louise, one of the younger women, outlined her anxieties at her own changing body. Louise (age 21) said:

“I have only had a few attacks and each time I find it strange how my body feels. My mind is saying – come on work properly leg – whilst my leg is just limping about and being unreliable. When I recover I always feel grateful that my body didn’t take me too seriously and decide to stay in a state of limpness! Joking apart the transition from a healthy body to a slightly disabled body is strange and I’m not used to it yet. I worry that I will get worse but then I think it’s important for me to stay positive for the future. If I get fully disabled then I get fully disabled. I couldn’t imagine it though”.

Louise highlighted that she is not used to the changing nature of her body when MS symptoms or attacks occurred. Louise further outlined:

“I do spend a lot of time worrying about this happening or that happening, and if I was honest I would say that although most friends think I’m totally strong and handling it, I’m not all the time. The aches and pains I don’t mind, and the numbness I can deal with, but vertigo, or blurred vision, as both effect my balance, that freaks me out, I have to say, because you feel nauseated, and you could drop over, or trip, you feel drunk, I can’t believe my body does that, that I have no control over what it does in that way, I used to think I could wish myself past those kinds of symptoms, but I can’t, and I’m not ready to surrender yet, and that makes it tough going”.

Josie also expressed her own personal challenges around the boundaries of her MS and how she dealt with them. Josie had recently taken to using a walking stick which she had had to use for a 3 month period and each day to enable her to go out.

However, Josie said that some days she just doesn’t go out as it is too difficult with her health although she always has time for fun with her small sons. Josie said:

“I was walking to see my dad and I was using the walking stick. This man who knows me vaguely stopped his car and shouted out the window – so what have you been doing? – I said ‘nothing, I have MS and I’m having a relapse’. He then just stared at me, said ok then, and drove off. Later on I bumped into him again

on my way back home and he started asking me if that was the disease that puts you in a wheelchair as you get older – can you imagine saying that to someone?”

Josie also said that she sometimes felt awkward because one day you can appear well and ok, and the next day you could literally be hobbling around.

Sammy (age 30) suggested that RRMS can be the worst type of MS for ‘*teasing you*’ (her emphasis) as you never quite know what’s coming. For Sammy, and some of the others, this made life unpredictable. Sammy says:

“When I had my first attack I thought that I would never recover. But I did and then I forgot for a while. When the MS returned I had no idea when it would go away, if it would go away and now I don’t know if it will stay away. Usually I am positive about my health for the future but we are all human and sometimes I cry buckets because I’m just plain scared. I have children to look after and being a single parent it freaks me out”.

Sammy displayed fear because she feels out of control when she experiences MS. She never knows when the attacks will happen and when they will depart. Even when she has recovered from an attack she starts to worry about when it will happen again thus leaving her in a state of helplessness. Liz echoed similar insecurities:

“I look ok now, and generally I do well, but there are no guarantees are there? I shy away from looking too far ahead because I don’t know how I’m going to be. I would hate to be bedridden – in fact I can’t think about it properly I prefer to switch off. I do have confidence that a cure could be found so mostly I would concentrate on that”.

Louise and Sammy both reveal that they do worry about an impending permanent disability on their bodies for the future. Although all the younger women tended to be knowledgeable about MS they had a vulnerable side about the future as there is still no identified cause or cure for MS (as outlined in Chapter 2). Liz said that she

worried about what the future would be like living with such uncertainty. Liz also discussed the possibility that her disability would become 'full-time' and she declared the thought petrified her.

Jesse was more upbeat about her future with RRMS. For Jesse embracing life was important to her particularly because of her past experiences with her family and her sexuality. Although she recognised the instability of MS she seemed determined to make the best of her life. She says:

“I am positive about the future. I have loads of things I want to do and I just want to get out there and live. I want to travel, I want to learn. I have lots of good things in my life now and I plan to keep them. People ask me if I'm worried about being disabled but what answer can I give to that. Yes, I have had health problems but I don't see them as ruling me. I don't see myself as being an ill person”.

Jesse was extremely feisty in her discussions about MS and did appear calm and in control of what was happening. She was still young though and could be refusing to accept that she has been diagnosed with a potentially chronic illness. On the other hand she could be trying to address the boundaries of her life that were changing, had changed and could continue changing.

Josie was very protective of her symptoms and experiences with MS. She was not comfortable with lots of people knowing about her MS and she tried to cover it up the best she could. She had recently started to be more open about it, but quickly shied away if she felt confronted by people's lack of understanding (see earlier quote on situation with the walking stick). This was echoed by Louise who said:

“When I say I returned to a normal healthy state after my attacks I think I am slightly exaggerating there. It is clear to me that since I ever experienced these

symptoms I have never felt fully normal, but I do have a state that I am used to. Yes, I think that's what I am referring to...I often think that I probably think about my body, and what I feel like too much, and so, I probably don't know yet, what's normal for me – does that make sense?”.

Josie linked in with this suggesting that she had forgotten what it felt like to be in her own body. Josie was in her early twenties when she first experienced MS and she said that she had never returned to normal after her first severe experience.

When discussing the future the younger women showed awareness for potential disability although they were generally positive about this. For example, Josie said:

“I learnt a long time ago not to worry about what you can't control. If I think about getting disabled permanently then it frightens me so I just don't go there. I get really cross when people refer to MS as a disabling disease because not everybody ends up in a wheelchair. I have bad days now – god, really bad days – but unless I tell people about it then they probably wouldn't know. And I am particular about who I tell. I even keep a lot from my dad because he gets so upset – and for him I think positively about the future as I know he would be gutted if he thought this was it, you know after what he went through with my mum and everything”

Although these were huge concerns for Josie she attempted to lead a normal life with her partner and young sons. Josie revisited the issue of the future a while later adding:

“I have young sons and a great partner. I have hope that a cure can and will be found. I want more children – I would love more children – but we will wait until I am over this current relapse. I secretly worry that new symptoms won't go away but if I dwelled on it I wouldn't get out of bed in the morning. It would be no good for Harry and Simon or Daniel (her partner) and life would be depressing. So you just get on with it and hope for the best – do you do that?”

Josie also directly linked her relapsing remitting MS to concerns about the future as she was worried that her relapsing remitting MS could change into a more permanent form of the disease and each relapse left her feeling uncertain about the future. She said:

“Because MS is so different between people it is worrying because you never know what can happen. If it was cancer like my mum had you can expect that certain things will happen and if you speak to other people in the same boat then you can have similar experiences. But MS is so different between people that sometimes it’s lonely”.

Josie highlights that MS has no clear boundaries either physically, practically, emotionally or in regularity. Like Kaufman (1999: 350) suggests in relations to stroke patients, *‘the threat is not the disease alone, but rather the existential awareness of loss, distortion, fear and entrapment that emerges on the journey of changing boundaries’*.

Summary

Chapter 10 has explored the women’s relationships with their changing bodies, which at times is often random and unsettling. Figure 10A identifies a 3 stage approach for exploring the process of adaption to the wide range of MS symptoms. The women expressed that due to the uncertainty of MS symptoms, quite often the boundaries of the body are in constant flux, which can be unsettling for them. However, within the process of change the women had gained strength and understanding about ‘their MS’ and how they could adapt in order to continue to develop.

Chapter 11:

Discussion of research study and further findings

Prologue

As outlined in Chapter 1, section 1.8, the focus of this study was to explore women's experiences with Multiple Sclerosis (MS) and look towards the women's own health understandings to assess the experience of MS over time. Key research areas included understanding the lived experience of MS include discuss and contextualising current medical processes; an engagement with temporal experiences of health problems over time; an examination of women's bodies within the medical system and an overall exploration of women's experiences living with MS and all that entails. This research study is situated within the sociology of health and illness, and incorporates a critical look at the social construction of women and health.

This piece of research has developed an original contribution to knowledge about women living with Multiple Sclerosis (MS). The thesis so far has outlined, contextualised and discussed multiple aspects of living with MS. This final chapter will bring together the key arguments conveyed throughout the study, and provide an outlook encapsulating the lived experience of MS for the women in this empirical study. Suggestions for future research will be outlined.

Introduction

This chapter brings together all the components of the thesis. Chapter 11 re-visits the research question, and addresses the key research questions of the empirical study. A discussion of the empirical findings of this qualitative feminist narrative study precedes a further discussion around suggestions for future research in the area of women and MS. Firstly, the use of reflexivity which has been a key component to this research is addressed.

11.1 Reflexivity and the empirical study

(Authors Note: 11.1 is written in the first person).

When I arrived at each of the women's houses for the interview I noticed them observe me – the way I walked, talked, held my cup when they offered me tea- they were looking to see if I had any visible signs of MS. They assessed me as I did them. Some of the women had obvious signs of MS which were alarming. One of the women I interviewed regularly had to stop because the nerves and muscles in her face would flinch and stop her from being able to speak. Another woman wet her pants whilst we were talking and we had to halt the interview whilst she changed. How did these instances affect me? I remember feeling compassionate – like you feel when a stranger falls in the street, or when you hear of other peoples misfortunes – and I found the women to be extremely dignified and admired them for their bravery which they often displayed during the interviews. But because of my work with the MS Society, the Neurological Alliance, and with meeting many people with MS I had expected to see different bodies. I know that MS has a wide range of visual and also hidden symptoms and although it is upsetting at times to see people in pain I was not shocked or overly disturbed by these experiences.

What did shock me though were the emotional conversations and the stories the women told me. How they told me about their lives and how they felt about their experiences with MS and other intimate issues which were delivered with an open honesty.

The women's stories of their lives were filled with emotional accounts of how they had coped with MS symptoms. At times during some of the interviews I found myself gaining comfort from some of the stories that the women told me. At other times I felt distressed by what they told me provoking feelings in me that felt new. A book on living with MS by Jelinek (2005) also recognises this point. Jelinek is a medical doctor in Australia who was diagnosed with MS several years ago. Jelinek (2005) recognised that his own diagnosis of MS brought about a series of changes for him that resulted in him addressing many buried emotional problems. Jelinek (2005: 175) said:

MS has caused me to reconsider everything about my life. It has brought very considerable pain, but also major insights, and a gradual re-shaping of my emotional life. I have been tested, and forced to face fears I have carried with me since early childhood. I have learnt an awful lot about rejection, abandonment, compassion, being judgmental, and about myself...I feel better for it

After talking with the 16 women during the interviews I drew heavily on the feminist model on page 88 as a research tool. This enabled me to develop a process which supported me to reflect thoroughly on what had occurred in the research encounters and for me to process any feelings I held in relation to the conversations. Figure 11 A

outlines the process I drew on.

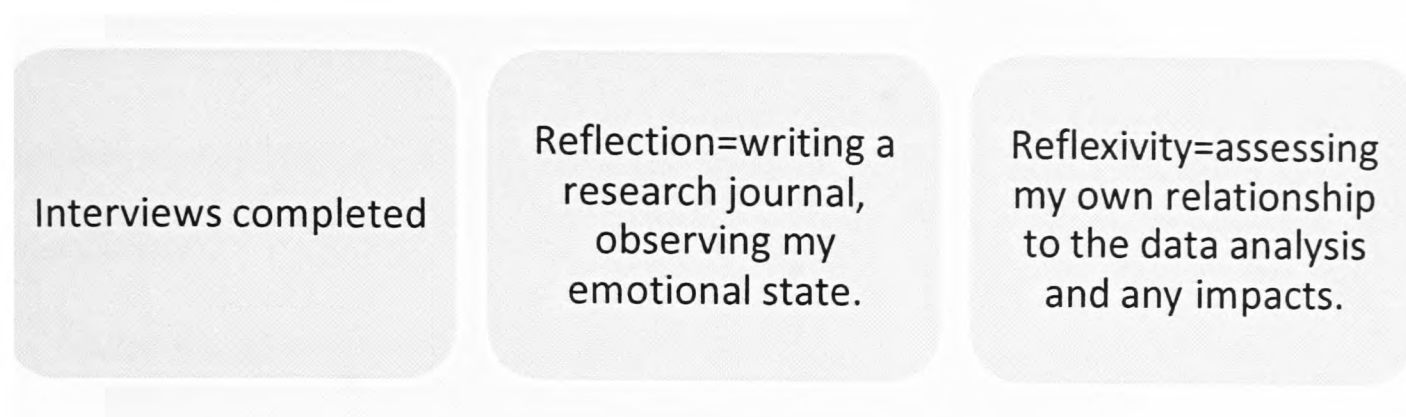


Figure 11A reflective practice model

During the research process I kept a research journal which assisted me with any informal notes and reflections I needed to make along the way. The journal was particularly useful when the research interviews were being conducted as it provided a space for me to write freely about any feelings that came up for me, during, and after the data collection. The research journal enabled me to identify, and be aware of, my own feelings within the process of data collection and data analysis. For example, extracts from my research journal show how I was surprised by the findings in Chapter 8 around the onset of MS symptoms. At the start of the research journey I had set out the questions which were focused around the past, present and future expecting that the women would focus solely on their experiences of their symptoms and how these impacted on their life. As each interview was completed I make notes around my surprise about this finding (Also the research journal reveals my surprise at the detail of the stories received in the research encounters). An extract below is taken from my journal half way through the interviews:

“I have completed 9 interviews now and I am finding that most of the women make sense of their MS by identifying a traumatic event, telling me in different ways, that they nearly expected to get something as their lives have always been emotional/busy/challenging. I am so interested in their interpretations, I never imagined that I would hear such focused and articulate stories, and told with such confidence, and like they are so sure about this. I really think it helps that they know I have MS, as they relax very early on, I can sense that, I do feel that this makes for more in depth interviews as well...”

Another extract from the journal highlights the revealing of information in the interviews:

“After the interview was finished and the tape recorder was off, *(Participant) started to tell me about how she was so pleased to take part, and how she finds it difficult talking to people about her MS, and she said she felt comfortable with me because I have MS too. I did feel a sense of connection with her and that she was relaxed, and I did feel a sense of her disclosing information to me that she hasn’t done before, and it’s because I have MS and she knows that, it could just be a one off, so I will see how it goes with the rest of the interviews”.

This final extract details my thought after all the interviews have been completed:

“I have completed all the interviews and now I feel really inspired by meeting all these different women and what they had to say to me. I feel so grateful that they shared such intimate details with me, I feel so sure now, that my own diagnosis of MS really did assist them in feeling relaxed, and just the knowledge that I understand what they are saying, when they describe their symptoms, because I know that sometimes words don’t do it, it’s just a feeling that is difficult to describe. This brings me to the role of intuition in data collection, I feel like I know that my diagnosis helped make the research more revealing, but how can I say that in a thesis!”

11.2: The Research Question

The research question: ‘What are the personal and health care experiences of women with MS?’ has been addressed in the thesis through the following channels:

- Recognition that MS has been defined and moulded predominantly within, and from, a medical perspective. This has been illustrated in Chapter 2 specifically and juxtaposed throughout Chapters 5-10 with the women’s narratives;
- An acceptance that ontologically women’s experiences of medicine have been shaped by cultural and gendered stereotypes and these stereotypes impact

upon the experience of the body for women living with MS when presented in a medical situation. This has been contextualised in Chapter 3 and applied with the women's narratives throughout Section 2;

- The women's lived experience of MS revealed several coping strategies and great resilience to outside inscriptions placed on their experiences. They also held their own reflective understandings of their lives and the greater meaning of living with MS for them;
- Through the use of the qualitative feminist narrative study, which supported the sequencing of the women's common stories, the empirical findings have been further developed into an original contribution of knowledge (through experiences) for women with MS.

11.3 Research findings

Chapter 1 mapped out the challenges that were made on a wider spectrum of gender, knowledge and power. Specifically, this research study looked at the division between the knowledge produced about MS, the medical treatment of MS and the women's real life experiences. Chapter 2 highlighted the research trajectories on MS, both historically and contemporary, and emphasised the dominance of medical and clinical research in this area. As further outlined in Chapter 2 the bulk of MS research is clinically based with a small section of research focusing on social care issues. However, it was concluded that although there were specific focuses of clinical and social care research there were still key fundamental questions to be answered in relation to MS. As Murray (2002) highlighted the same questions are still being asked about MS today as they were 150 years ago. From that perspective medical knowledge is at odds on how to address the needs of people with MS as the key

clinical perspectives of MS are conflicting in thought (Jelinek, 2010). This was reflected through the women's experiences with healthcare and accessing information about treatment plans. Chapter 7 specifically concluded that many of the women found it difficult to locate a clear pathway for supporting the symptoms of MS within healthcare.

Furthermore, the findings in this qualitative feminist narrative study have revealed the disjointed trajectory between medical responses to MS symptoms and the women's real life experiences of MS. Chapter's 5 and 6 show the numerous interactions the women experienced with GPs, mostly without having their subjective experiences recognised in the consultation situation. Table 6.1 displayed the time it took to from experiencing MS symptoms to being diagnosed with MS, ranging from 3 months to 27 years – with a substantial amount of years being the predominant time scale for the majority of the women. On further exploration of the women's stories it was revealed that the main reason for the long-time scale between the onset of symptoms to diagnosis was due to lack of hospital referrals by GPs. Moreso GPs had often misdiagnosed several of the women as having depression and anxiety. Several of the women remarked that they had taken medications for depression, and a couple of the older women had been prescribed tranquillisers for many years.

Chapter 3 further highlighted some key debates around women, medicine and bodies. One of the key advancements in Chapter 3 determined that women's bodies were culturally and socially constructed within society, and references were made to bodies and medicine in relation to the social construction of illness for women. For example, the questions around women's hormones and anxiety related disorders by doctors

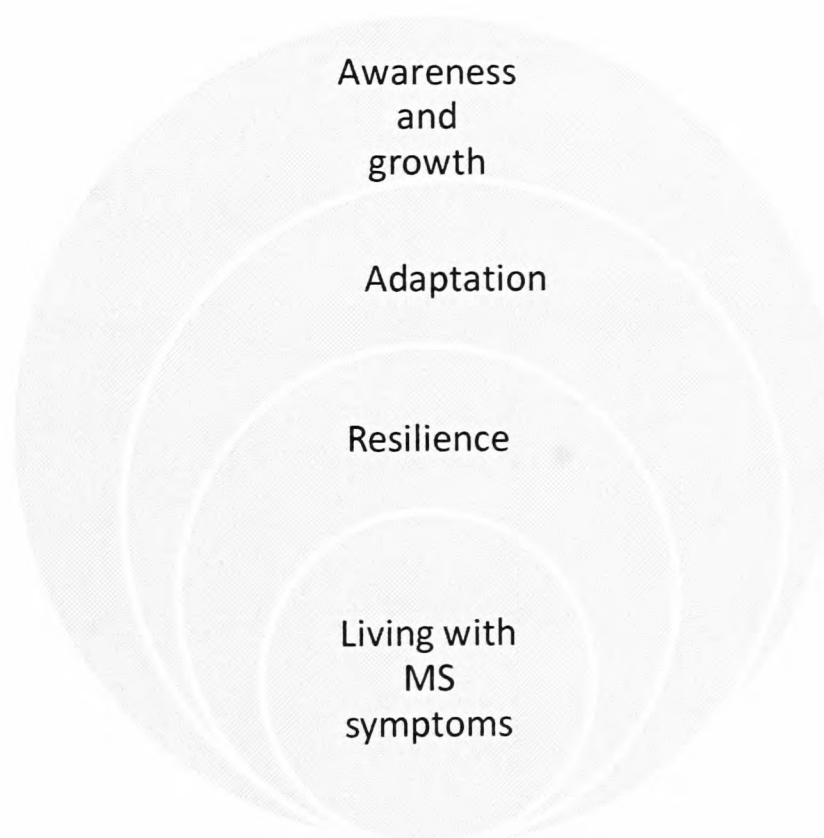
have been raised since second wave feminism (see Chapter 1, p.23). Chapter 5 detailed the women's narratives re-telling their experiences in medical situations. Often, it appeared that the women's subjective understandings of their bodies were not heard in the space of the doctor/patient relationship. Instead the response to the women's descriptions of their symptoms was to offer and prescribe anti-depressants. Furthermore repeated visits to the GP over many years, and up to 27 years, resulted in the women doubting their physical experiences with many of the older women accepting they had depression for a period of time. Several of the women had also felt discouraged from attending their GPs as their concerns were devalued on presentation.

The current treatment plans for people with MS are currently focused on 2 key medications of Copaxone (please see appendix 1 for BNF description) and Beta interferon (please see appendix 1 for BNF description)(see page 48). Chapter 7 particularly highlighted the difficulties for the women, in first of all accessing information about these treatments, and secondly being eligible to take them.

Furthermore, the women's stories about medical and social care supports illustrated the struggles they experienced when trying to locate a clear pathway of support for someone living with MS. In some instances there were positive experiences which mainly centred around a health professional taking an interest in the symptoms of MS and attempting to get to know the women on a one to one basis and understand the impacts MS had on their physical bodies. These positive supports were identified by the women as being local rather than national.

The impacts a diagnosis of MS had on the women's personal relationships were explored in Chapter 9. Although some of the women expressed sorrow at the changes they had experienced in their lives they also highlighted a sense of hope and personal development. This was identified through the way they told their stories, and their ability to reflect on, and articulate, their experiences. Many of the women's recollections of their experiences with MS showed resilience. For example, apart from 2 of the women, the women had coped with experiencing frightening and distressing symptoms, and still carried on with their day to day lives. Many of the women commented that they felt grateful to be able to reflect on their lives, a space which the experiences associated with MS had provided them with. This had encouraged the women to make sense of their own lives, for example as seen in Chapter 8.

Figure 11B identifies some of the positive gains for the women



11.4: Temporal experiences

The semi-structured interviews were developed to gain an understanding of the women's experiences over time. The women discussed their issues with MS over time

and talked about a period of adjustment (these were specifically highlighted in Chapters 8, 9 & 10). For the most part that experience had occurred whilst they had no confirmed diagnosis of MS. In reality the older women coped with symptoms of MS without any recognition that they were experiencing a chronic illness. Often, many of the older women especially had coped with MS symptoms whilst being informed by the doctors that they were suffering with depression. Even if the women felt that they weren't experiencing depression but another health issue, they had to get on with life as the presentation of their symptoms were not recognised by their doctor initially. Over time many of the women had developed strategies for coping with their symptoms whilst continuing their day to day lives.

One aspect of the women's experiences with MS which was present throughout all 6 data analysis chapters was the characteristic of the uncertainty of MS symptoms. The random and surprising nature of MS symptoms, is recognised medically (Jelinek, 2010; Halper & Holland, 2011) and could be considered one of the most challenging aspects of living with MS. The women's narratives identified the uncertainty of MS as being a hindrance when presenting in a medical situation, and also a personal barrier to work through when living with MS. In many ways the uncertain nature of MS had pushed the women to further explore their personal and physical boundaries.

Chapter 8 presented some of the women's own understandings for their onset of MS. The women had reflected on the beginning of their symptoms and identified a key event that they attached to understanding why MS had entered their lives. Chapters 9 and 10 explored the personal and physical boundaries on the women's relationships – both with people they shared their lives with, and also with experiencing their

physical bodies. Figure 10A outlined a 3 stage approach for exploring the process of experiencing MS symptoms.

Women living with MS have largely remained invisible within the discourses of health, particularly in the current literature and more specifically in the long-term plans for neurological healthcare. For the older women interviewed they felt they did not fit into the current healthcare system. The women's own stories of their health problems significantly suggest that the current medical, social and healthcare model of the National Health Service (NHS) does not reflect the real life experiences of these women - particularly older women – and consequently detracts from their support and treatment. There is a huge gulf between the medical discourses that address the challenges of MS and the lived recollection of their own experiences^{ix}.

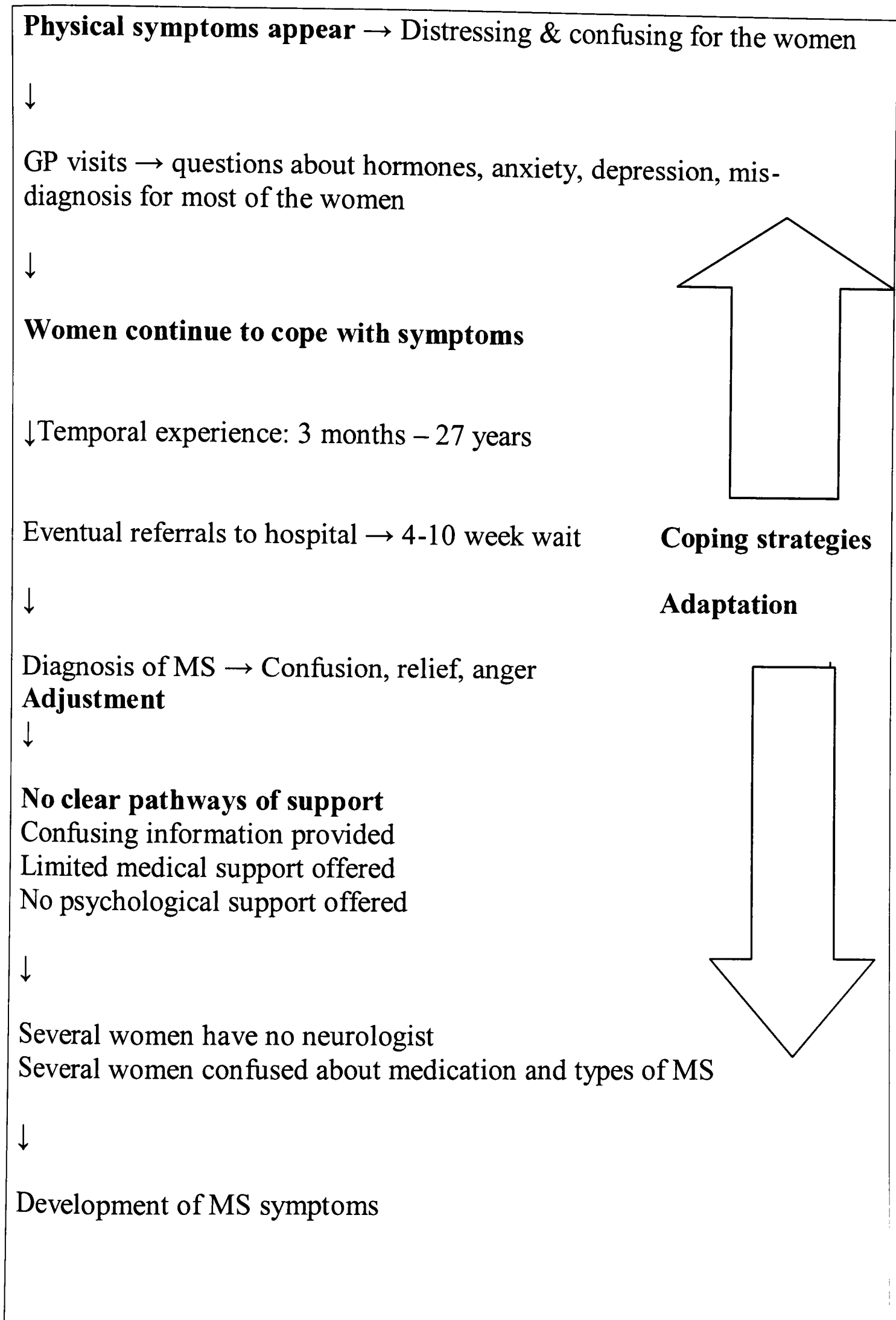
11.5: The lived experiences of women with MS

The women in this study have experienced great impingements due to their experience of MS and quite often have had negative consequences for them. Their experience of MS had been shaped, and influenced, by their interactions with medical institutions. Chapter 3 specifically positioned medicine as being a social constructed institution that has historically shaped the knowledge around women's bodies, and in this study, about MS. They have revealed how the women coped with the situations they faced and how, within that, they have created their own knowledge and information about MS.

Firstly figure 11C identifies and presents the lived experience of MS and health services as told through the women's narratives. This map details the lived experience

of MS and emphasises the oppressive role played out through medical institutions towards the women at times. It is clear from the map that the point of visiting GPs with their MS symptoms halts the women from progressing further in their quest to obtain information about their experience of physical symptoms which are occurring. For some of the women this spanned out up to 27 years. It is also clear from the map that the women did cope living with MS symptoms even when they did not have adequate knowledge or support about what was happening to their bodies. Currently, many of the women in this thesis do not have regular contact with a neurologist.

Figure 11C is a map of the lived experience of MS and health services



11.6: Identified bodies within the lived experience of MS

Figure 11C highlights a map which demonstrates some of the social processes the women were faced with, and engaged in, at the onset of their MS symptoms, the diagnosis of MS and their interaction with health services. In this next section the lived experience of MS is developed further by identifying bodies which represent some of the women's experiences.

The data analysis chapters and empirical findings have outlined the women's lived experiences recognising the relationship between the self and the body. Table 11D identifies 6 body types derived from the women's experiences. These will be discussed further now, reflecting on, and linking in with, the analysis chapter 5 to 10 and how this relates to the research question and the lived experiences of MS.

Figure 11D: Identification of bodies to understand the women's lived experiences of MS.

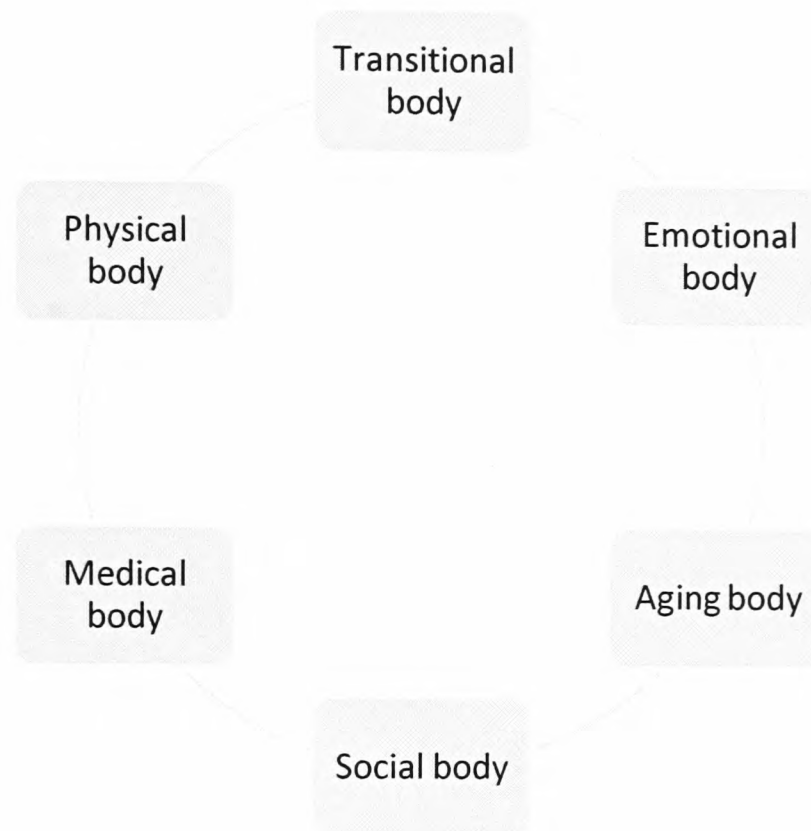


Table 11.1 details the body types of the lived experience of MS

Body type of lived experience of MS	Description of body type	Empirical findings
Physical Body	The physical body exhibits the symptoms of MS, through disabling parts of the body, sometimes with obvious physical symptoms, or with invisible physical symptoms.	Symptoms of MS experienced by the women; the bodily experience of MS as described by the women; Specifically identified in Chapter's 5 & 6.
Medical Body	The medical body reflects the women's experiences when they reported the symptoms of the physical body in a medical situation.	Experiences of the women when reporting their MS symptoms; the experience of the women in health systems to support their MS symptoms. Specifically Chapter's 5, 6 & 7.

<p>Social Body (Douglas, 1970)</p>	<p>The social body as a lived experience of MS. In this empirical study Douglas' (1970) understanding of the social body '<i>constrains the way the physical body is received, always modified by the social categories through which it is known</i>' is drawn upon. This can be viewed in the way the women's bodies were imprinted with understandings of gender, and how they felt confused between the knowledge of medicine, and what they actually experienced.</p>	<p>Mis diagnosis of the physical and medical body; the women's experiences of being questioned about their hormones and being diagnosed with anxiety and depression; the social body represents the women's experiences of symptoms, disability, employment and other highlighted experiences by the women during Chapter's 5-10.</p>
<p>Emotional Body</p>	<p>The emotional experience of the body as an aspect of the lived experience of MS can be viewed through the empirical study specifically around the coping and adjustment processes outlined by the women around their personal relationships.</p>	<p>The emotional body can be viewed in the women's expressions of their MS experience, but specifically in chapter 8, where they relate emotional experiences to impacting on their physical body. Specifically identified in Chapter's 8, 9 & 10.</p>
<p>Transitional Body</p>	<p>The transitional experience of the body – from being able, to disabled, to being able again (example of RRMS). Also, the bodily boundaries changed sporadically with the emergence of new and changeable symptoms.</p>	<p>The women experienced a transitional body from the start of their MS symptoms and prior to a diagnosis of MS. This can especially be noted in Chapter's 9 and 10.</p>
<p>Aging body</p>	<p>The aging body is recognised throughout the interviews with the older women. The invisible experience of some of the women through their age was revealed through their stories, such as, not being told about current treatments. Also all the women in the study expressed a fear of declining physical health as they got older realising that MS is a progressive disease.</p>	<p>The aging body represents the temporal experience of the older women. Specifically identified through Chapter's 5-10.</p>

11.7 The research contribution of this study in comparison to other relevant research studies about MS

The findings from this qualitative feminist narrative study have some commonalities with the findings from similar studies which have also explored people's experiences with MS. There have been several studies that have focused specifically around examining the process of a diagnosis of MS which have shown similar findings to this current study. For example, a study by Johnson (2003) looked specifically at receiving a diagnosis of MS and the processes surrounding the diagnosis. Johnson (2003) conducted interviews with 24 people who already had a diagnosis of MS. The interviews were conducted in 2 cohorts of 12, one set conducted prior to the implementation of an MS nurse programme in the UK, and the second set afterwards. Similar to the findings of this current study, Johnson (2003) found that there was dissatisfaction around the diagnosis of MS and how the information was received about the diagnosis. Chapter 6 of this thesis details the women's stories around diagnosis and the women's recollections of how this occurred. The findings from Johnson's (2003) study highlighted that the role of the neurologist could be reviewed, as many people felt abandoned and isolated once the diagnosis had been given, with several participants feeling like the neurologist withdrew once the diagnosis had been given to them, suggesting that the neurologist felt their work had been completed. Similarly this current study found that the women had mixed experiences with consultants' and neurologists with the majority of the women expressing that they would have liked more time to ask questions around the time of diagnosis. Johnson's (2003) study concluded that feelings of abandonment and isolation are high in people with MS around the stage of diagnosis.

Furthering the work of Johnson (2003) and others (Caplan, 1996; Heeson et al. 2001) a study by Solari et al. (2007) highlighted the difficulties identified in communicating a diagnosis of MS to people. The aim of Solari et al. (2007) study was to explore personal experiences of the communication of the MS diagnosis. This process of receiving/communicating a diagnosis of MS was also explored in this current study and was set out as one of the aims of the research study. The participants of Solari's et al. (2007) study were split into 2 focus groups: 1 group contained people who had a diagnosis of MS and the other group consisted of healthcare professionals including a neurologist. Solari's et al. (2007) further objective was to put together a communication aid for people newly diagnosed with MS. The themes identified in the focus group of people with MS included poor levels of support from medical practitioners when a diagnosis of MS was being given, little or no information from practitioners during the diagnosis meeting which added to the stressfulness of the situation and people felt that there wasn't enough time given to the meeting from neurologists. All participants said they felt the diagnosis of MS should be communicated as soon as possible, and although all agreed that an appropriate setting (such as a private room) was important, allowing more time for the diagnosis was difficult due to time constraints on neurologists due to work loads. Solari's et al. (2007) findings further suggest having appointments booked in advance with the same neurologist for continuity of care would support people with MS to manage their symptoms in a more supportive capacity (a finding also in this current study).

Johnson's (2003) and Solari's et al. (2007) research findings recognise the need for sensitivity around the diagnosis of MS and suggest that poor communication can impact negatively on the person being diagnosed. In this current study looking at the

personal and health care experiences of women with MS the diagnosis of MS is described in the research findings as similar to the conclusions of both Johnsons (2003) and Solari's et al. (2007) studies once the women were engaged in hospital practises (the emphasis of this current study being that the women found referrals to the hospital difficult). This current study further explored the process of diagnosis by examining the women's experiences prior to diagnosis. Similarly Isaksson and Ahlstrom (2006) explored people's conceptions of MS pre diagnosis. They found that the pre conceptions of MS ranged from people feeling terrified and having negative images around disability and MS to people associating MS with being in a wheelchair. The women in this current study also reflected similar understandings about MS.

Isaksson and Ahlstrom (2006) found that initial symptoms for people were vivid in people's memory and created anxiety and fear in people. Chapters 5 and 6 of this thesis specifically highlight the women's initial symptoms and describe them as being vivid in their memory also as well as detailing the fear and anxiety they experienced. Furthermore, this current study develops the concept of anxiety and identifies it as a theme for exploring the women's experiences when they presented with MS symptoms at their GPs.

Johnson (2003), Solari (2007) and Isaksson and Ahlstrom (2006) all recognise that poor communication in healthcare settings resulted in people with MS being left to feel vulnerable. Isaksson and Ahlstrom (2006) specifically detailed that long waiting times for appointments impacted negatively on people with MS, and they often felt rushed when attending the consultation. On receiving a diagnosis of MS Isaksson and

Ahlstrom (2006) outlined the continued uncertainty that people felt. For example, similar to the responses in this research study, people felt that the future was unpredictable and uncertain around their prognosis, due to each person being different with symptoms. They also reported that confirmation of symptoms was a relief which was reflected in the women's stories in this study. Although some of the older women in this current study expressed confusion on their diagnosis of MS as they had been told they had anxiety and depression for such a long time it was initially difficult to digest the new diagnosis of MS. Furthermore, the experience of living with MS symptoms and attempting to obtain medical support was explored further in this current study.

Isaksson and Ahlstrom (2006) identify the process of the person with MS being vulnerable after the diagnosis of MS (and whilst waiting) to acquiring strength through their experiences. This current study also identifies this, and further develops this journey of personal development through exploring the women's stories in more depth. For example, this current study looks at the women's experiences with personal relationships, with how they experience their bodies, and how they came to understand the onset of their MS symptoms. Isaksson and Ahlstrom's (2006) study included a larger data collection of 61 participants, whereas this current study looks in-depth at the experiences of 16 women. This current study provides a more detailed look at patient and doctor interactions and medical explanations at the onset of MS symptoms whereas the studies included for discussion here tend to have larger data collection and as a consequence the findings are not as detailed. For example, the findings from this current study examine diagnosis processes and further this

discussion to offer a more in-depth look at the impact a diagnosis of MS can have on personal relationships.

11.8 The strengths and limitations of the research study

This qualitative feminist narrative study was developed to attempt to dissipate the power relationships which can occur in research processes, specifically between researcher and participant. A key strength of this study, and one which guided the methodology to being a qualitative feminist narrative study, is my own experiences of being a researcher with a diagnosis of MS (as highlighted in 11.1). The reflexivity model on page 84 details some of the research tools used before, during and after the research encounter. Underpinning the overall study was the awareness of the implications of conducting the research and the role and responsibility that falls to the researcher throughout the process. Due to the research being openly subjective a positive rapport developed throughout all the research encounters. Also the symptoms of MS can be extremely confusing, and often difficult to describe to other people, and my own experiences and depth of understanding around this very intimate issue further strengthened the quality of the data collection. For example due to a shared understanding of MS the conversations and portrayal of experiences could be further explored due to the shared understanding of MS. This has added to the stories which the women told, and has added to the trustworthiness of the findings.

The study has further detailed a set of stories from women covering a vast range of ages. This was an important feature of the research as the findings chronicled the similar experiences identified from the women aged between 21 – 71 years old. This proves to be one of the strengths of the study and is reflected in the findings, which

provided an in-depth account of common experiences for women living with, and experiencing MS symptoms, in a range of situations. The conclusions of the study were also able to determine that healthcare options for the women were dependent on age.

The findings of the research have outlined that medical professionals have applied gender stereo types, and this is specifically highlighted in Chapter's 5, 6 and 7. From this perspective one of the strengths of the research is the common narrative of the women interviewed which represented this experience of gender stereo typing by GPs. However, as the male experience of attending doctor's surgeries with MS symptoms is not represented in this study a comparison cannot be made until further research is carried out including men. Although the women's experiences in this study have highlighted very specific gender stereo types, such as being related to hormones, childbirth and menstruation, the research could be further explored to examine if men experience similar stereotypes when presenting with MS symptoms. For example, further research could explore if men are diagnosed with depression and anxiety when presenting with MS symptoms.

The analysis of the data was descriptive particularly around the common stories identified within the women's interviews. The decision to offer a more descriptive understanding of the data was to uphold the feminist principles of the study which included being based on equal status between the researcher and participant. Before and after each interview I discussed the common stories developing out of the research (especially moreso when several interviews were completed) and to have imposed a higher level interpretation to the data analysis may have felt inappropriate,

and also may have required further discussion with the participant. This process could then have compromised the researcher's responsibilities to ensure a safe and honest exchange in the research encounter.

In qualitative research the validity of research can be recognised through exploring the concept of trustworthiness. Denzin & Lincoln (1994) draw on the criteria for trustworthiness as being credibility, transferability, dependability and confirmability (see Denzin & Lincoln, 1994; Bryman, 2001). In terms of credibility respondent validation is a technique used often in qualitative research to ensure the credibility of qualitative research. It involves the researcher providing each respondent, or participant, with an account of his or her findings. This can further develop into the respondent validating the accounts presented to them, or further commenting to assist in shaping the outcomes of the research. In terms of this study it was decided after the pilot interviews that further contact with participants may not be appropriate due to the emotionally charged nature of their accounts. This was further confirmed during, and at the end of the data collection, when the women regarded their interviews as 'gifts' to a trusted researcher, and may not have wanted further feedback. It would also have challenged the feminist principles underpinning the research to have sent paper copies of their transcripts, and/or any analysis, as the content could have been distressing for them. In terms of transferability of the research, the rich accounts of the women's narratives assisted in creating a cultural context for their experiences with MS, and furthermore, their common narratives created a social world about personal and health experiences for women with MS. The dependability of the research is defined mainly in Chapter 4, and through the use of the reflective journal. All stages of the research were recorded, and regular supervision was recorded and attended to as part of the code of ethics of research at the University of Salford.

11.9 Research Conclusions

This research project has raised a number of questions. These questions have focused on the role of medicine and the interface of gender and MS. These questions were most prevalent in Chapters 5 and 6 where the women's experiences with medical professionals were both disturbing at times, yet good examples of the limits of medicine and MS. Chapter 3 further emphasised the cultural influence of women's bodies and medicine. Nettleton (2005) pointed out '*the history of medical knowledge can be regarded as an objective science but the application of medical knowledge is not*' (Nettleton, 2005).

It was also clear from the empirical findings that receiving a diagnosis of MS was important for the women. Some of the women reported that this was to confirm they were sane and had not imagined their experiences. One story told by Emily contextualises this point:

“When I got my diagnosis of MS I said to the neurologist – well at least I know I'm not mad now. He just looked at me – the one thing I remember is he gave me no information, no one else to talk to, and you know what he didn't even have a box of tissues. I always remember that – no bloody tissues. When I cried he turned away but luckily my mum was with me to offer some kind of comfort”.

On her first available opportunity Emily visited her local doctors to inform them she was not mad and she had been diagnosed with MS.

The findings from this research study have offered a new way for thinking about MS and women and lays the foundations for more exploratory and focused research work in this area. Specifically, it would be valuable to look at the views of key clinicians in

this area to attempt to bridge the gap between medicine and the lived experience. For example, Reingold (2002) and Compston (2004) both recognised as clinicians that current research trajectories on MS need to be widened to include the opinions and experiences of people with MS.

These empirical findings also revealed that the women's current care practices were an issue which appeared to link to the current pathways available to the women.

Chapter 7 specifically highlighted the positive and negative experiences as told by the women. As the women expressed in this study, there are more barriers to healthcare access than there are formulas for getting there. This sadly stops many women pursuing avenues as they find them too stressful.

Key contributions from this research study

- The length of time the older women had lived with MS symptoms prior to receiving a diagnosis of MS;
- The diagnosis of anxiety and depression particularly for the older women when presenting with MS symptoms;
- The willingness of doctor's to apply gender stereotypes to the women's presentation of their MS symptoms;
- The process of negotiating with gate keepers to obtain medical investigations;
- The highlighted differences in the health related experiences of older and younger women, specifically the access to services being a key feature here and the sharing of information;
- The embedded experience of MS in personal relationships with husbands, family members and friendships;

- The women's own lay explanations of the onset of their MS symptoms.

Future work in this area

One key question to be raised at the conclusion of this study would be around the medical classification of MS. From the background research of the literature review it may be beneficial to re-examine the classification of MS. The women's narratives highlighted that there was confusion around the current recognised types of MS. Also, these criteria for different stages of MS did not appear to be applied consistently, especially at the local level of service provision. Furthermore, for those women who did not access a neurologist there was confusion around the type of MS they had. This transferred into disempowering some of the women as they still did not hold all the relevant information about their health status. Although some studies (Johnson, 2003 and Solari, 2007) have attempted to address these processes already further detailed work in this area is still needed. Chapter 2 outlined the historical and current research trajectories in the area of MS. The literature review showed that the majority of research has been, and still is, within a clinical context – although there are clear tensions between various clinical perspectives. These tensions unfold in reality to produce an unclear medical pathway and at times confusing medical discourse for both professionals working in health and for people living with Multiple Sclerosis (MS). Further work in the future could be:

- To re-examine the classification of MS drawing on the expertise of multi-disciplinary teams;
- To have a more detailed look at hospital processes and the sharing of information between health professionals and people with MS (or suspected MS).

Secondly, how the definition of MS is applied in practice by specialists in the area of MS needs attention. It could be that more specialists need to be trained in the area of MS specifically and that people with MS have the choice to be able to access a consultant who has a specific interest in MS. Also more communication between hospital consultant and GPs could assist in ensuring the symptoms of MS are identified at the local level. From this perspective there could be the development of an audit tool of MS symptoms which can be provided to GP surgeries to share knowledge on the wide and varying symptomatic nature of MS. This would assist in earlier referrals to the hospital for further tests and a quicker diagnosis of MS. Future work in this area of information sharing around MS could include:

- Specifically an audit tool could be developed for GPs and health practitioners who work at the local level in order to provide further training in the area of MS. This could also include the experiences of people with MS.

Furthermore clinical implications of this research study could provide a platform for exploring the role of medical practitioners when faced with the symptoms of MS. The use of an audit tool could further develop into training around communication skills for doctors and an awareness of stereo typing when assessing presenting symptoms. Also training and supporting people with MS to share their experiences in forums where change can occur such as in teaching hospitals, advocacy support groups and disability rights organisations.

Also further research in the area of examining the personal and health care experiences of people with MS could be extended to the following:

- To conduct a study which includes men's experiences;
- To further explore the women's own lay explanations for the onset of their MS symptoms and extend that to gain feedback from men;

Finally, this thesis in part uses MS as an illustrative way of exploring health provision within a healthcare system which relies heavily on the interpretations of illness as defined by medical discourses. The limitations of MS knowledge undermines the agency of these women who participated in this study, and as shown throughout the analysis chapters, succeeded for a period of the women's lives. By assessing the women's temporal experiences it is suggested that a more detailed contribution to MS research exists in understanding MS through subjective experiences. The women's own stories of their health problems significantly suggest that the current medical, social and healthcare model of the National Health Service (NHS) does not reflect the real life experiences of these women – particularly the older women – and consequently hinders from their support and treatment.

Appendix 1

British National Formulary (BNF) Descriptions taken from website www.bnf.org (accessed 01/09/2012)

1. Glatiramer acetate (also known as Copaxone)

Glatiramer is an immunomodulating drug comprising synthetic polypeptides. It is licensed for treating initial symptoms in patients at high risk of developing multiple sclerosis, and also for reducing the frequency of relapses in ambulatory patients with relapsing-remitting multiple sclerosis who have had at least 2 clinical relapses in the past 2 years. Initiation of treatment with glatiramer should be supervised by a specialist.

2. Interferon beta

Interferon beta is licensed for use in patients with *relapsing, remitting multiple sclerosis* (characterised by at least two attacks of neurological dysfunction over the previous 2 or 3 years, followed by complete or incomplete recovery) who are able to walk unaided. Not all patients respond and a deterioration in the bouts has been observed in some. It is also licensed for use in patients with a single demyelinating event with an active inflammatory process, if it is severe enough to require treatment with an intravenous corticosteroid, and they are at high risk of developing multiple sclerosis. Interferon beta-1b is also licensed for use in patients with *secondary progressive multiple sclerosis* but its role in this condition has not been confirmed.

3. Steroids

8.2.2 Corticosteroids and other immunosuppressants

Prednisolone ([section 6.3.2](#)) is widely used in oncology. It has a marked antitumour effect in acute lymphoblastic leukaemia, Hodgkin's disease, and the non-Hodgkin lymphomas. It has a role in the palliation of symptomatic end-stage malignant disease when it may enhance appetite and produce a sense of well-being (see also [Prescribing in Palliative Care](#)).

The corticosteroids are also powerful immunosuppressants. They are used to prevent organ transplant rejection, and in high dose to treat rejection episodes.

Ciclosporin a calcineurin inhibitor, is a potent immunosuppressant which is virtually non-myelotoxic but markedly nephrotoxic. It has an important role in organ and tissue transplantation, for prevention of graft rejection following bone marrow, kidney, liver, pancreas, heart, lung, and heart-lung transplantation, and for prophylaxis and treatment of graft-versus-host disease.

Tacrolimus is also a calcineurin inhibitor. Although not chemically related to ciclosporin it has a similar mode of action and side-effects, but the incidence of neurotoxicity appears to be greater; cardiomyopathy has also been reported. Disturbance of glucose metabolism also appears to be significant.

Sirolimus is a non-calcineurin inhibiting immunosuppressant licensed for renal transplantation.

Basiliximab is a monoclonal antibody that acts as an interleukin-2 receptor antagonist and prevents T-lymphocyte proliferation; it is used for prophylaxis of acute rejection in allogeneic renal transplantation. It is given with ciclosporin and corticosteroid immunosuppression regimens; its use should be confined to specialist centres.

Belatacept is a fusion protein and co-stimulation blocker that prevents T-cell activation; it is licensed for prophylaxis of graft rejection in adults undergoing renal transplantation who are seropositive for the Epstein-Barr virus. It is used with interleukin-2 receptor antagonist induction, in combination with corticosteroids and a mycophenolic acid.

Antithymocyte immunoglobulin (rabbit) is licensed for the prophylaxis of organ rejection in renal and heart allograft recipients and for the treatment of corticosteroid-resistant allograft rejection in renal transplantation. Tolerability is increased by pretreatment with an intravenous corticosteroid and antihistamine; an antipyretic drug such as paracetamol may also be beneficial.

Appendix 2

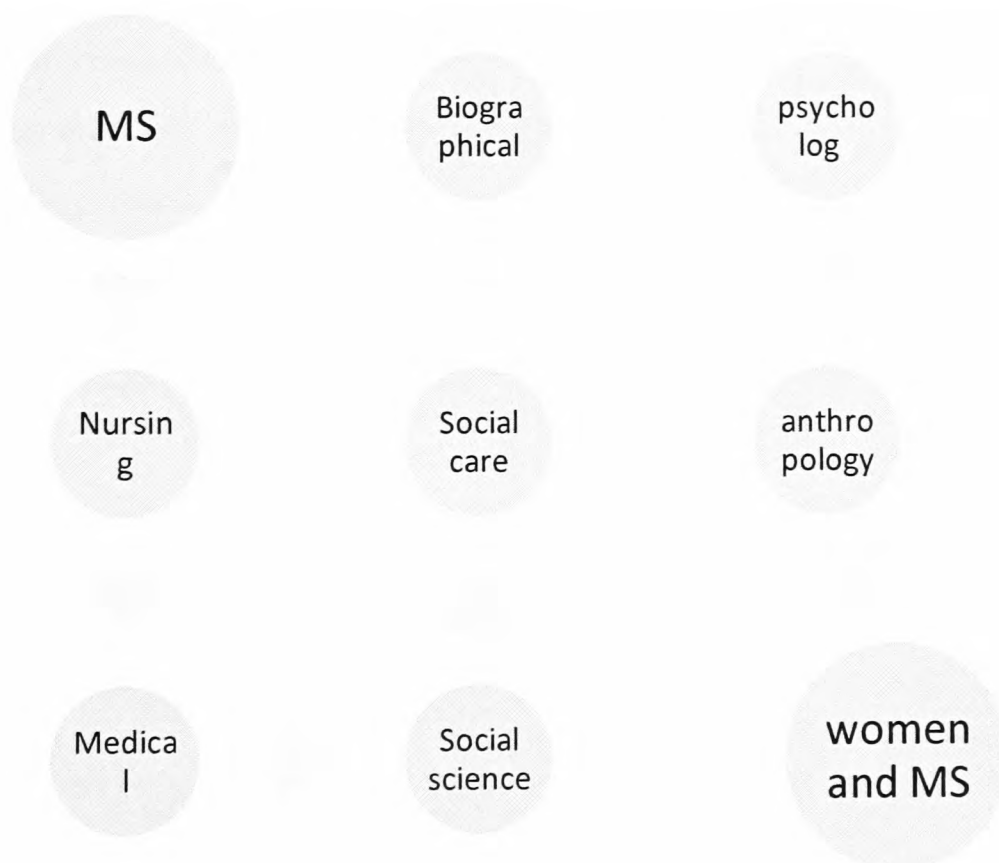
Introduction

This appendix document refers to the process of the literature review for Chapter 2 specifically. The reviewing outcomes are presented in table 1a. Below the 4 questions of the literature review are listed. These 4 questions were derived through the research question as discussed in Chapter 1.

These are the 4 questions of the literature review:

1. What does the literature say about the emergence of MS into a medical narrative?
2. What are the key medical and social care research themes for MS?
3. What does the literature on MS say about the knowledge that has been, and continues to be, developed about MS?
4. Is there any literature that addresses women's issues and MS specifically?

These questions evolved after exploring the issue of MS.



Sources used for literature review: University of Salford library system, Lancaster University library system, UCLAN library system.

Online resources and databases including Webspirs; AMED; HMIC: HELMIS; HMIC: Kings Fund Database; Sociological Abstracts; Sport Discus; OVID BIOMED; PsycINFO; Science direct.

World Wide Web.

Dates reviewed: the main review was carried out between 2003 – 2004, and was then updated yearly. It was further fully updated in December 2011. Each review used the same reviewing system.

Reviewing protocol for journal articles:

1. Text would be identified by word search as outlined in table 1a;
2. Abstract would be read, and article would be graded 1, 2, or 3;
3. 1=listed for review; 2=potential for review; 3=discarded as not suitable;
4. At the end of each review session, articles would be placed into the endnote system in the categories outlined in table 1a;
5. Graded 1 and 2 articles were placed in the endnote system, and further reviewed for relevance, or for further references and signposts.

Reviewing protocol for books:

1. Book would be assessed for relevance;
2. References checked for further review leads;
3. Same grading system as for journals;
4. All abstracts and review notes placed into endnote system for organisation.

Library resources: Social Sciences, Nursing, Medicine, Social Care, Women's Studies, Biography

Topic	Number of texts found	Books	Journal Articles	Other/specify
Nursing Care and MS	542	219	317	6 online resources
Nursing care and chronic illness	542	132	410	
Medical and MS and treatments	448	55	378	15 online resources
Social care and MS	64	19	22	22 online resources
Social Science/anthropology and MS and chronic	47	3	44	

illness				
Biographical and MS/Chronic Illness	38	12	26	
Multiple Sclerosis	48	6	42	
Alternative therapy and MS	23	3	20	

Appendix 3

Ethics Approval and Protocol for fieldwork

UNIVERSITY OF SALFORD

Research Governance and Ethics Committee

Ethical Approval Form for Post-Graduates

Ethical approval must be obtained by all postgraduate research students (PGR) prior to starting research with human subjects, animals or human tissue. A PGR is defined as anyone undertaking a research rather than a taught degree, and includes MRes, MPhil and PhD. The student must discuss the content of the form with their dissertation supervisor who will advise them about revisions. A final copy of the summary will then be agreed and the student and supervisor will 'sign it off'. The applicant must forward a hard copy of the Form to the Contracts Office once it has been signed by their Supervisor and an electronic copy emailed to the Research Governance and Ethics Committee through Max Pilotti m.u.pilotti@salford.ac.uk.

(The form can be completed electronically; the sections can be expanded to the size required)

Name of student : Louise Blinkhorn

Course of study : PhD

Supervisor : Professor Steven Shardlow

1. Title of proposed research project

Older women's lives: A study into the lived experience of older women with Multiple Sclerosis

2. Project focus

Historically women's bodies have been shaped and controlled through the discursive formations of medical authority. The discursive shift of medical authority from the belief that disease existed separate from the body to the modernist idea that disease arose from

within and could be mapped through the human body, significantly changed medical practice (McNay, 1994). The doctors 'gaze' on the 'visible' body powerfully contributed to the increased surveillance of bodies and the social control of bodies (McNay, 1994). More specifically, women with Multiple Sclerosis have battled against ideas about women's bodies and sexuality, both of which are couched within the power of the biomedical model and the doctors 'gaze'. This thesis will explore the lived experience of women with Multiple Sclerosis through the use of narrative and storytelling. The study is exploratory in terms of finding out about the women's experiences and critically analysing the stories in terms of the discursive formations and practices of medical authority, and the construction of female bodies.

3. Project objectives (maximum of three)

- Explore the meaning and experience of the everyday lives of older women with MS
- Attempt to give meaning and understanding to the bodily experience of MS for these women and look at any implications of the dominance of the bio medical model
- Explore the impact of the medicalisation of women's bodies on their embodied identities

4. Research strategy (for example, where will you recruit participants? What information/data collection strategies will you use? What approach do you intend to take to the analysis of information / data generated?)

The aim of the research is to explore the experiences of women living with Multiple Sclerosis. The research is a challenge to the biomedical model way of thinking about bodies and aims to explore the relationship between the dominance of the biomedical model and the lived reality of women living with a disease.

The recruitment of participants will take place through advertising (see attached advertisement). I have also attached a target information sheet that details the specific criteria of the locations that will be targeted. This is a feminist piece of research and will focus on women and women's bodies. The project will be carried out in the North West of England due to time, travel and cost. These are the only stipulations placed on the study and I aim to keep the recruitment of participants as open as possible.

The data collection will be conducted through one to one interviews with up to twenty participants. These may be collected over a six month period and may involve a series of smaller interviews if agreed with participants. The reasons for this are:

- The participants may be more tired and prefer smaller interviews due to their

disabilities

- Drawing on a feminist model of research shorter interviews over a period of time allows for reflection on the research process for both the researcher and the researched
- It may form a more relaxed and in-depth relationship between the interviewer and interviewee therefore enhancing the data collection

Participants will be recruited on the understanding that they will be engaged in the research process in terms of the focus of the interviews and, as the data will be analysed as it is collected, the participants can be engaged with the research process and discuss developing themes. At all times throughout the research process respondents will be informed of the research and process.

5. What is the rationale which led to this project (for example, previous work – give references where appropriate)

There are several reasons for the development of this project. Initially I was diagnosed with MS myself and as an undergraduate researcher conducted a small scale study into the lives of women living with MS. This study introduced me to literature surrounding the body, women's bodies in the healthcare system and set me on a path to challenging the biomedical model. The small scale study suggested that further research into this area could explore the relationship between the lived reality of MS and women's bodies in the current healthcare system. Current research projects around MS are predominantly configured within a biomedical model understanding of the body and this study aims to challenge the social implications of the power of medical authority.

6. If you are going to work within a particular organisation do they have their own procedures for gaining ethical approval – for example, within a hospital or health centre? NO

If YES – what are these and how will you ensure you meet their requirements?

Not applicable

**7. Are you going to approach individuals to be involved in your research?
YES/ NO**

If YES – please think about key issues – for example, how you will recruit people? How you will deal with issues of confidentiality / anonymity? Then make notes that cover the key issues linked to your study

Recruitment will take place through advertisement. I will not approach any individuals leaving participants to choose to join/find out about the study. All participants that join the study will be covered by issues of anonymity and confidentiality. Any published material that evolves from this study will not identify any person that took part. All information about participants will be securely kept and disposed of after a five year period. This will be highlighted in the consent form.

8. More specifically, how will you ensure you gain informed consent from anyone involved in the study?

Underpinning the research is a feminist framework. The issue of informed consent will be addressed from the outset of the project and will be discussed on recruitment of the participants. This will be achieved through the following:

- The aim of the study will be discussed with participants with the aims and objectives highlighted in an accessible form before recruitment is finalised
- The researcher will be honest, reflexive and will discuss all stages of the research process with participants
- The researcher will ensure that participants can leave the study at any point and their data collection will be withdrawn
- The researcher will provide participants with a written consent form that is accessible to all participants and will go on to discuss this with respondents throughout the process
- Participants will be able to withdraw at any point during the study.

9. Are there any data protection issues that you need to address? YES

If YES what are these and how will you address them?

The storage of the confidential data collected will be securely held for five years when it will be destroyed.

10. Are there any other ethical issues that need to be considered?

Please attach:

- A summary in clear / plain English (or whatever media/language is appropriate) of the material you will use with participants explaining the study / consent issues etc.
- **A draft consent form – again in whatever media is suitable for your research purposes / population.**
- **A copy of any posters to be used to recruit participants**

Remember that informed consent from research participants is crucial,
therefore your information sheet must use language that is readily understood
by the general public.

Projects that involve NHS patients, patients' records or NHS staff, will require ethical approval by the appropriate NHS Research Ethics Committee. The University Research Governance and Ethics Committee will require written confirmation that such approval has been granted. Where a project forms part of a larger, already approved, project, the approving REC should be informed about, and approve, the use of an additional co-researcher.

I certify that the above information is, to the best of my knowledge, accurate and correct. I understand the need to ensure I undertake my research in a manner that reflects good principles of ethical research practice.

Signed by Student

Date

In signing this form I confirm that I have read and agreed the contents with the student.

Signed by Supervisor

Date

*Please also complete and sign the attached Risk Assessment Form.

Protocol for fieldwork

Participants will be recruited through an advertisement (appendix 1). In line with ethical approval participants will initially contact the researcher via telephone or email. Prior to starting the study the researcher will outline the aims and objectives of the study to participants. The researcher will provide the participants with some information about the study (appendix 2) although this will be optional dependent on the participants' circumstances. For example the researcher will ensure that the participant is able to read the information, or they have someone who can look at the information with them. The researcher will also offer to discuss the information with the participant over the phone or in person.

The interviews will be carried out at the convenience of the participants although in line with ethical approval the researcher will assess all potential participants in terms of her own safety. For example, the researcher will make common sense decisions based on information provided by the participant(s) and draw on her connections with the voluntary sector to confirm identity. If unsure of any potential participants the researcher will meet them in a public space or withdraw them from the study.

Each interview will be arranged via the telephone and the study will be discussed thoroughly before the interview. This will be done through providing each participant with an information sheet (appendix 2) or discussing the information sheet over the telephone. Any questions or queries about the study will aim to be resolved over the telephone before the interview commences if at all possible. The researcher recognises that questions may arise before, during and after the interview but with the aim of minimising any disruptions the researcher will provide as much clarity to the study as possible before hand.

Each interview will start with the consent form (appendix 3). Like the information sheet, the consent form will have reached the participants before the study and hopefully any questions will have been addressed. However, the beginning of the interview will be allocated for any questions or discussion about the consent form. The researcher will also reaffirm the obligations of the consent form and read through

the main stipulations of the consent form with the participant. Before the interview can begin the researcher will ensure the consent form has been acknowledged and signed by all parties. Again recognising the protocol of the ethical approval (appendix 4).

Each interview will be tape recorded at the agreement of each participant. It will be made clear to each participant that the interview can be halted at any point for any reason or stopped altogether indefinitely. This is part of the consent agreement and is in line with the ethical approval stipulations.

Each interview will be semi structured, with the structure being identified through the themes. These themes are a journey of temporality and will be grouped within narratives of:

- History
- Present
- Future

Each theme will be explored drawing on a range of questions that may be changed or modified with each participant. As explained by Mishler (1989) the key to the interview is to listen to the experiences of participants and reduce as much power/leadership from the situation as possible. The data will be analysed drawing on narrative analysis with the interview being shaped by experience and temporality. The following questions are representative of each theme but should be taken as a guide as they are not conclusive of each interview.

History

1. Can you pinpoint a time when you first experienced symptoms of MS?
2. How long did you experience MS before a diagnosis was made?
3. What was the time period between first experiences of MS to getting a diagnosis? Would you like to tell me about this?

Present

1. How do you manage the symptoms of MS on a daily basis?
2. Do you think it has a big impact on your life? Please explain?

3. How do you cope with your MS?

Future

1. How do you see the future living with MS?
2. Do you think your MS is helped by medical treatment? Please explain.
3. Do you think anything could be improved for people with MS?

It is important to note that the semi structured interview will be formatted through theme rather than question. For example in the pilot interviews the questions were used as a guide and each interview started through general chatting between participant and researcher. The researcher is a woman with MS and has been open and honest about this through the advertising. This stimulated conversation at the start of the interviews and was a good way of getting the interview started.

In line with ethical approval the researcher will ensure that the participants can be guided to relevant resources if the interview raises any challenges or distress. The researcher has experience in the voluntary sector and will ensure to meet the needs of the participants whether directly or to signpost relevant information.

Each interview will be guided by the participant in terms of time although the researcher anticipates a cut off point of an hour and a half. If it is felt the research would benefit from another interview with the participant this will be discussed after the interview between the researcher and the participant.

Each interview will end with the researcher discussing the themes raised in the interview and discussion on whether a follow up interview is required. Each participant will have the contact details of the researcher and may wish to contact her after the interview with any queries. The researcher will ensure that each participant is kept informed of every stage of the research process.

Appendix 4 – Advertisement

Do you have Multiple Sclerosis?

A study is going to be carried out looking at the experiences of women living with MS. The researcher aims to explore the reality of living with a disease and would like to hear from any women who would like to share their experiences. If you would like to find out about this study please contact Louise on 01524 62531 or e mail Louiseanne4@aol.com

Thank-you

Appendix 5 – Advertisement campaign

Target sheets for distribution of advertising for recruitment.

NHS trusts in the North West are within Cheshire, Cumbria, Lancashire, Liverpool and Manchester.

Cheshire	Lancashire	Cumbria	Liverpool	Manchester
Chester and Ellesmere Port Community Health Council	Blackpool. Wyre & Fylde Hospitals NHS Trust*	Bay Community NHS Trust, Barrow-in-Furness	Aintree Hospitals NHS Trust	Central Manchester Healthcare NHS Trust
Countess of Chester of Hospital Trust	Bolton Hospitals NHS Trust	Eden Valley Primary Care Trust	Chester & Halton Community NHS Trust	Mancunian Community Health NHS Trust
East Cheshire NHS Trust	Burnley Healthcare NHS Trust		Liverpools Women's hospital NHS Trust*	Manchester Health Authority
Halton General Hospital NHS Trust	Burnley Healthcare NHS Trust		Mersey Care NHS Trust	Mental Health services of Salford NHS Trust
Mid-Cheshire Hospital NHS Trust*	Bury Healthcare NHS Trust		Royal Liverpool and Broadgreen University Hospitals NHS Trust*	Salford Community Health Care NHS Trust
Stockport Health Community*	Calderstone NHS Trust, Lancashire		Southport and Ormskirk NHS Trust	South Manchester University Hospitals NHS Trust
Warrington Community Health Centre NHS Trust*	Chorley & South Ribble NHS Trust		Walton Centre for Neurology and Neurosurgery NHS Trust*	Trafford Healthcare NHS Trust
Wirral & West	Communicare			

Cheshire Community NHS Trust Wirral Hospital NHS Trust	NHS Trust, Accrington			
	Community Healthcare Bolton NHS Trust			
	East Lancashire hospitals HNS Trust			

Charities contacted in North West

Cheshire	Lancashire	Cumbria	Liverpool	Manchester
MS Society: Chester & Ellesmere Port; North Cheshire Branch; South East Cheshire Branch;	MS Society: Blackpool & Fylde; Chorley & District; Preston & Westmorland; Lancaster & Morecambe Branch	MS Society: Barrow in Furness branch; Kendal Branch;	MS Society: Southport & Formby Branch; Warrington & District; Wirral Branch;	MS Society: Bolton & District; Salford district; Manchester Branch; Oldham Branch; Pendle Branch; Rochdale & District; Rossendale Branch
Neurological Alliance: Cheshire	Neurological Alliance: Morecambe Bay; Preston	Neurological Alliance: Kendal Branch	Neurological Alliance: Liverpool	Neurological Alliance: Manchester

These were the initial places that advertisements were sent to. Generally I called each organisation to ask them if they would display an advertisement for me – or the best way for them to do it. This was followed by a letter as shown below:

29 February, 2004

Dear Sir or Madam,

RE: ADVERTISING

Following a recent phone call I enclose the following posters for display. I also enclose an advertisement for your magazine. To recap, I am from the University of Salford and I am carrying out research on women with Multiple Sclerosis.

Sincerely,

Louise Blinkhorn
Ph.D Student

I also sent out advertisements to some magazines. These magazines were:

- MS Matters advertised in the March/April 2004
- Local magazines attached to local organisations. These ranged from advertisements in local Neurological Alliance magazines, MS Society, Health Matters and free local magazines that were picked randomly.

Appendix 6– Information sheet

This study wants to explore the experiences of women living with Multiple Sclerosis. The study wants to look at issues of the women's identities and their relationship with MS. The study wants to focus around the women's experiences and the research will be open and flexible in discussion. The researcher for this project is based at the University of Salford doing a Ph.d. The researcher is also a woman with MS and that is why the research is focused around women. The researcher feels that the experience of MS is specific for women and wants to explore this. Issues such as:

- What is it like to live with a debilitating disease over a period of time?
- How do the women deal with any issues on a day to day basis?
- How do they feel about the healthcare system?
- How does living with MS impact on their lives?

The study has evolved from earlier research carried out that suggested that older women with MS were very much excluded from the management of their bodies within the healthcare provision of the NHS. This study aims to build on that and explore the experiences of women living with MS. The researcher thinks that the current legislation for people with MS is quite poor and hopes that this research can somehow contribute to the importance of listening to peoples experiences. The researcher is also involved in local charities such as the MS Society and the Neurological Alliance and has a lot of experience in this area.

Appendix 7 – Consent form

Consent form

This study wants to understand the experiences of women living with Multiple Sclerosis. The research aims to explore issues important to women with MS. For example what is it like to live with a chronic disease over a period of time? How do the women deal with any issues on a day to day basis? How do they feel about the healthcare system? These are the kind of themes that the study wants to focus on. Also the research wants to listen to the women's stories of having MS and highlight what is important to them.

The study will involve face to face interview(s) with the participants and this will be discussed with each participant. Throughout the study the researcher will discuss the research direction with each participant and discuss any developing issues coming out of the interviews. At all times the information about the respondent (such as name, address) will not be disclosed to any other parties. At any point in the study the participant can withdraw and stop the interview without explanation. The tape recordings and transcripts will be destroyed or given to the participant to dispose of. Overall, the data collection, such as tape recordings and transcripts will be kept in a secure place for five years after the research has taken place then destroyed.

Please could you read through the following information and if agreed sign the consent declaration at the end. Thank-you.

1. I am willing to take part in this study.

2. Details of the study have been clearly explained to me.
3. I have had the opportunity to ask any questions about the study.
4. The researcher has assured me that all my details and information about me will not be revealed to any other parties.
5. Any work that may be published out of this study will not identify me.
6. I may withdraw from this study at any point.

Signed..... (researcher)

Signed..... (participant)

Appendix 8 – Dates of interviews

Name (Changed for confidentiality)	Date of interview
Emily	14/06/2004
Alice	12/09/2004
Rebecca	13/09/2004
Josie	22/06/2004
Iris	05/05/2004
Doris	06/05/2004
Doreen	15/08/2004
Louise	06/06/2004
Jesse	04/06/2004
Sammy	03/06/2004
Suzanne	14/09/2004
Jenna	01/02/2004
Alison	30/09/2004
Liz	28/07/2004
Linda	26/07/2004
Gill	25/07/2004

Appendix 9

Example of transcript – Emily’s interview transcript

Emily interview (Name changed to protect her identity)

Interview held at Emily’s house

Conducted 14/06/04

Transcribed by Louise Dawson

Pretext

Prior to the interview I rang Emily and talked to her about the consent forms, the interview, and any questions she might have. I also sent her an information sheet to look at prior to the interview. When I arrived at the interview I spoke to Emily about the interview again and we signed the consent form together. I explained again the importance of confidentiality. I discussed with Emily what would happen during the interview and how we could stop the tape at any time to have a break, or finish the interview altogether. Emily stated that she was looking forward to the interview.

Interview transcript

L: Louise (the researcher) E: Emily (interviewee)

L: (after tape check). Well, thank-you Emily for taking part in this research. Before we start, please remember that, if you want to stop the interview at any point just tell me and I will turn the tape of immediately. Or is you get tired and you have just had enough of talking, please just let me know. Does that sound ok to you?

E: That’s ok Louise, I think I will be ok, but thanks, I am happy to be doing the interview, the research sounds interesting and I’m interested to see what your doing. I do voluntary work and I run an information centre so I am always happy to get involved in MS related things, if you know what I mean. Anyway, it’s not often that someone asks you about how you are doing with MS. and

what got you here, to this point, living as I do with MS and generally getting frustrated! **Laughs** Since I spoke to you on the phone the other night I was thinking about the long time I have been doing this, you know moaning and griping about having MS or something that links to it. Before I start rambling off is there any point you want me to start at?

L: Like I said on the telephone Emily the research is about women's experiences, basically just what happened from the beginning. Can you remember when you had your first experience of MS?

E: Yes, well like I said to you Louise, I can go through what happened to me, I will probably go on and on so feel free to halt me if I'm going to fast or you want to ask any questions. I told you that I do this twice a year with the student nurses so I am pretty good at just reeling it off so, I will go through then just ask if you need to, ok?

L: That's fine Emily

E: No problem, so would you just like me to talk, like I'm talking as if I'm talking to the student nurses

L: Yeah, just go ahead

E: Do you mind me asking how old you are?

L: I'm 31

E: Crikey so you're just young aren't you. And how old were you when you were diagnosed?

L: I was about 26 when I found out I had MS but I probably experienced it from being about 16/17.

E: Yeah, yeah that's a common story.

L: So how old were you when you were diagnosed?

E: Well I'm 42 now and I've been diagnosed 4 years, but I had what turned out to be a relapse about 10 years ago, and it does explain a lot from being about 18, 19, 20.

L: That was the same for me. It answered a lot of questions.

E: Yeah, it makes my mother feel quite bad but it does answer an awful lot of questions.

L: Really. What kind of questions does it answer Emily?

E: So much about my life, my whole bloody life. Did you not find that?

L: I did find that actually, that things made sense to me once I had got the diagnosis in some ways. I have heard that often from people with MS. Its funny isn't it?

E: Yeah, I do think there is always something not quite right about people with MS.

Lots of laughter

E: Anyway I will tell you about mine, my experience really yeah. 4 years ago I was diagnosed, but I will go right back to my first relapse and then that brings us forward into where I'm at today.

L: Yes, that sounds great.

E: About ten years ago, it was a Sunday and we were stood outside, and I said 'ooh I have this tingling sensation in my back'. I didn't know what it was but I'd been to see my great grandma who had shingles so I rang the doctor and said

I have this tingling in my back, been to see my grandma who has shingles, can I catch it – he said ‘oh yes it sounds like shingles, go home take paracetamol’, you know that kind of thing. The next morning when I woke up I thought I’d had a stroke, and I could feel these tingles moving up and down my spine and back and I could track where they were going. I was frightened. The next morning when I woke up I couldn’t move my left side, there was weakness, (it was) I just thought I’d had a stroke, it was so scary. I rang the doctor, then went to see the doctor, and erm, this was a few days later because I was unsure what to do and I thought it was probably not a stroke as I was still here. I went to see the doctor a couple of days later, yes that’s right, and as doctors do he said I was overweight, depressed and I had too much time on my hands. That was it; he said ‘the trouble with young women nowadays is they have too much time to think’. He gave me some Prozac

L: Yeah, yeah, this has been such a common story

E: Yeah, oh my God, I’d took my dad with me as I’d been going to the doctors on and off for years with various things such as depression or this funny thing, or that strange feeling, and I’d got to the stage where I just thought everybody thought I was mad. So I’d took my dad and came out to the waiting room, (sorry I’m going to swear now) and I said too him ‘well that was a fucking waste of time as he thinks I’m mental’. All I came away with was a Prozac prescription. I went back to my mums, you know, absolutely distraught, didn’t know what was occurring, carried on, I did go back and see another doctor, who referred me to a neurologist, but this was all about six months later. In the meantime this numbness and walking and holding my arm like I’d had a stroke lasted for about 3 months”.

L: Yeah, yeah

E: Got in to see the specialist, and he sent me for an MRI – this was my first MRI scan ever. Went back to see them and they said you have some wear and tear in your neck. You know, go home. I thought ok, wear and tear in my neck, that’s it, maybe arthritis. You go home and you get on with it. By this time I had a six year old and a

five year old, you just get on with it, etc etc. I always had this weakness on my left side, always knew it was there but I just got used to it

Louise: Ok, right

E: 4 years ago in the august I was cleaning someone's fridge, I used to be a cleaner, and erm, I felt this tingle in my face the size of a penny.

L: Right, ok.

E: I thought aw and it itched a bit and I didn't think no more about it but it lasted for about 2 or 3 weeks. And I'd gone to see the doctor about something else and I just happened to say to him I have this tingling sensation in my face, just a tiny penny shape, cause I wasn't sure if I had an abscess or something, so he says well you know we'll send you to see the neurologist. I said ok. So 6 months later again, that will be august, so I went to see the specialist, that's about 5 years ago, and he said, did all the tests, you know pushing, pins and that reflexes and stuff

L: Yeah, I know those tests

E: I never really thought anything and he says well we'll send you for an mri, well I never heard anything and by Christmas my face, all my face had gone numb on the right side, tingling in my eyes, tingling in my ears, so I went back to the doctors and said I'm a bit worried, I actually thought I'd had a beastie bite or something, and I said this tingling got worse, I said I'm supposed to be going for an MRI and he said we'll get that hurried along, never heard anything, never heard anything, this was early January, February my arms, hands had gone, my arms had gone really heavy and tingly and odd, and I couldn't really put my finger on it, the descriptions and that were just odd.

L: Yeah

E: Went back to the doctors and I said you're supposed to have jived up this MRI, and I found out they hadn't done anything. They hadn't jived it up at all. They

hadn't done anything. So this time I insisted on the letter being sent etc etc, so I got the letter confirmation sent saying that they were waiting for a quick appointment. Anyway a few more days went by and my face became very painful, very tingly and very painful. I was back at the doctors, and they were telling me the obvious, 'you need to lose weight', and 'are you taking your Prozac?' so I was really pissed off with the doctors by this point. But anyway I went one day with my mum because I thought a bit more support and they may not tell me I'm overweight, you know if my mums there. So I went to see this doctor and I said to him look my head feels like its been chopped in half, filled with concrete, and it's all tingly, and I'm frightened to death, I don't know what's happening. I said to him I don't know if I've got a tumour growing in my head, I don't know what it is. By this time we had already gone through all this the doctor turned round to me and said 'what you're describing sounds like stress. I suggest you go home, forget about it, and you try and de-stress'. With which I just my bag up and walked out.

L: Yeah, yeah

E: So that was in the, it would be the end of March, April, end of April I went to, I got my MRI, my MRI and then I had to go back, no erm, then I saw the doctor who said about me being stressed, em then I was called back for a CT scan and a lumbar puncture. That was in the April. By this, nobody had mentioned anything, I had got myself convinced because of this lack of sensation in my body that I had got motor neurones, and I'd got myself having that.

L: Yeah I remember going through that, thinking about motor neurones especially.

E: You know, erm, and it used to be at the best it could be MS at the worst it could be motor neurones. All the time I was in contact with the doctors you know and I made a plain, nuisance of myself especially after this guy said to me you know go home and rest.

L: Yeah, yeah,

E: So I had been a bit of pain at the doctors, going and saying do you have my results, can I have my results, and then I finally rang the hospital erm, and I got a letter from my consultants on the 28th May to say you will get your results from the hospital on the 4th July. And I thought I can't wait that long to find out if I'm going to die. So I rang them up, I said I can't wait til that long to find out if I'm going to die or whatever, and she said actually we have got a cancellation this afternoon, so I took it. So at 3.00 on the 28th May cause that date is stamped into my head I walked in to see the consultant, me and my mum. He sat me down and said how are you? I said well I have been better, hoping not to get worse but have been better. He said have you any idea what you've got? So I said well I think it's MS, I'm hoping it's not motor neurones, so I'm hoping it's MS. And he turned round and said 'yes it is'. I went oh. The tears just rolled down my face. He looked at me and said 'are you alright?' how I didn't swear I don't know, I do tend to swear (laughs) and I said 'at least I'm not mad'. Cause by this time I'd convinced myself it was all in my head mum kept saying to me are you sure, she was going to pay for me to get my thyroid done and that. When I got my diagnosis of MS I said to the neurologist – well at least I know I'm not mad now. He just looked at me – the one thing I remember is he gave me no information, no one else to talk to, and you know what he didn't even have a box of tissues. I always remember that – no bloody tissues. When I cried he turned away but luckily my mum was with me to offer some kind of comfort.

L: Yeah yeah, I see

E: All stuff like that so I was absolutely devastated, well you know yourself, you are absolutely devastated

L; Yeah, it's a difficult time. Most people say that.

E: Since then I've made it, it's like a mantra, everytime I talk to student nurses, ms nurses, anyone erm I say to them why don't you have a box of tissues on the bloody desk instead of having to get up and go and get them out of the cupboard, you know, or I could have took tissues with me, but it's that that stays in my mind, that he didn't even have a tissue for me to blow in to. So anyway we were in 5

minutes if that, but he did say to me I will make you an appointment with the MS nurse if you like, and I came away with nothing. I've said since to MS nurses and consultants and anyone that will listen, that you know when you're going to diagnose someone with MS or with motor neurones, you know that you'll be doing that, so why not give them a little card a little business card that gives you the national centre telephone number or the local contact. I walked out and I thought well what do I do now? You know luckily my friend had the internet, but I came away with nothing.

L: Yeah, oh yeah, that's terrible

E: I felt utterly lost. Got to the car park and I just broke down, I said to mum, who the hell's going to want me now. I'm a single mum, just to tell you, when I had the first bad attack where I thought I'd had a stroke, my marriage broke up, so when I was diagnosed I was a single parent, overweight and now I had MS. The only person I ever knew with MS I had been a bridesmaid for and she's in a wheelchair highly disabled and totally dependant. A lot of the MS affected her brain, her cognitive skills and everything so I came away terrified and this was it, this was how I was going to end up, this was me. You know that's all I knew and for 3 weeks I didn't ring national centre, a lot of people don't, and that's what I thought was going to happen to me. I was like oh my god how am I going to end up like that; I have no husband to look after me, terrible, terrible, horrible horrible time and I went to see the MS nurse and I realised that it didn't always have to be that bad. It's still bad but you know, at least you have someone proper telling you that, so I got all the information and that, then went back to work. I had been off sick for nearly 6 or 7 months and they gave me a start date cause whilst I'd been having these neurological tests they didn't want me at work, you know

L: Where did you work at that time?

E: Local care home, they were quite happy for me to be at work but they just kept saying to me well they would need to put me on with somebody else, you know, and I was fine with that because the last thing I wanted to think about was a load of moaning old people, so they were quite happy for to be off sick. They weren't

getting rid of me they were being supportive ringing up and seeing how I was and if they could help at all, they weren't saying we can't have you because.

L: So they were supportive to you?

E: Yeah and they were like friends to me. So I arranged to go back to work, they gave me another month off to come to terms with what had happened like that helps (laughs)

L: That was good of them though wasn't it?

E: Yeah, it was. So I went back to work. I completed 3 weeks of shifts, I'd been to beaver castle to see a friend camping, came home, sent the kids to the childminders and I was sat watching Duffy, the vampire slayer, and it was half past 6 in the evening, and I was sat and thought my bottom feels very tingly, ooh so do my legs, oh my god, and within 10 minutes I couldn't feel my legs, shook my arms and the feeling had gone, I was so scared, so absolutely so scared, by this time, oh sorry I'm jumping ahead a bit, after I'd been diagnosed my nan told me the local MS branch met at her end of town, so I'd been down there a few times and this nice middle aged lady gave me her telephone number, and although most of them were a bunch of winging gits, that's what you do to placate everybody that your coming to terms with having MS. Anyway, this night when I was watching the tele and I couldn't feel my legs, having panicked and gone stupid and fetched my mum in, I rang this support officer, the one I'd met at the meeting and she'd given me her number and I told what had happened and I said 'what's happening to em?' and she said 'I don't know'. Well what do I do, who do ring, you know she said 'I don't know, have you rang your doctor?' I was so scared, I was really so scared and I know this lady had MS herself, but how naff to tell be she didn't know when I was obviously petrified. She had said to me if you need anything or any help just call – so I did. And I was terrified

L: I bet that was awful.

E: So, I then... is this alright Louise?

L: That's great Emily, that's fine. Are you ok to carry on?

E: Oh yeah. So, that was the 22nd July, I remember because it was the night before my 38th birthday that this big relapse happened. And erm, this was classed as a big relapse. Within 3 or 4 hours, my mum and dad are very practical and they had fetched me a wheelchair so I could sit at the back door and have a fag, so basically I was having a 'big' relapse when I had just got my diagnosis of MS and I couldn't get about on my own. My family helped me to get the house organised – literally in one day they came and moved everything downstairs. My bed, I already had a bathroom downstairs, and they made everything accessible for me. My family are really practical people but I was devastated. I cried and cried and couldn't get my head round it.

L: So what happened next?

E: The next day, my 38th birthday, my sister and her husband had bought me a card saying 'hey sister get legless' would you believe it eh? **Laughs.** I mean they came to see me having bought this card and had no idea I had declined into this relapse and felt bloody dreadful. It said it all for me. I just laughed – this is MS! Anyway my dad and mother brought my bed downstairs, put the dining table away and I was settled into the kitchen, like I said I have a downstairs bathroom. I have a very practical family and that's what happened, it was a bloody awful whirlwind and I was totally and utterly out of control. You know I couldn't get out the back for my fags properly. Since then however I have realised that I would be able to feel my legs because they are still like that now you just learn to live with them.

L: So your legs never came back?

E: Not particularly no, they did do in strength but it is still the same sensation. If I relax and close my eyes I can't feel my legs.

L: Ok.

E: But all my MS, or a lot of my MS tends to be sensation.

L: Would that be all over your body or just in certain places?

E: Yes, erm my hands everything, in fact the only things of my body which I can really really feel and know is there is my throat. It's really bizarre. Anyway that was my birthday when that all happened. Again my friend put me in touch with the district nurse and within 48 hours had organised care, the OT, social services, she'd even organised with the local hospice that I could hire one of their electric scooters. Of course I didn't have the confidence to drive, well I couldn't have driven. That lasted probably 2 or 3 months but that involved the relapse then the process of getting better. The hospital offered me intravenous steroids (please see appendix 1 for BNF description) but that meant going into hospital and when you've got a 12 and 11 year old who are terrified the last thing you want to do is whip of to hospital for 3 days. So I had oral steroids (please see appendix 1 for BNF description) which is over a 6 or 7 week course and so it just got to where you know, I mean if I had known what I know now I wouldn't have been in the wheelchair for very long...(pause)

L: What do you feel would be different?

E: it was the sensation of not being able to feel my legs that made me frightened to walk, and if someone had said to me, this is what happens in MS then I would have known and maybe tried to get out of the wheelchair sooner, but I thought I couldn't walk. It's very easy with MS to stay disabled because of the uncertainty of the what happens to you, total random symptoms. There just wasn't anybody there to talk to about MS, I would ring the MS nurse and she wouldn't give you an awful lot of information and then the doctor, or the neurologist say that you just have to get on with it, which you do, you know, but when you don't know what's happening to you it's difficult to recover because you're so bloody scared.

L: Yeah, yeah,

E: Actually Louise can we stop for a few minutes whilst I go to the loo and make a quick drink?

L: Yeah course. I will just turn the tape off.

Break from interview

L: Right then I've turned the tape back on now. Are you ok and ready Emily?

E: Yeah, lovely cup of tea thanks Louise. Right then, so I was talking about recovery after a relapse wasn't I? Yeah I was going to tell you about my dad. Well it was about 7 weeks after the relapse and my dad came round and he sat down and he said 'right then I'm not being mean but (and it was a big but) the longer you stay sat in that chair the longer it will take you to get out of it'. Basically he said use it or lose. But it was the best thing he did for me. I got out of the chair, I fell, stumbled, it took a while but I tried, and I think had he not pushed me I would still be there now. I got a frame first then went onto a walking stick, but this was difficult and still is now because I have really weak wrists and arms, no real strength there you know. I find elbow crutches work ok for me.

L: And would you use them all the time?

E: no, I would use them a lot but not all the time. Again I have the confidence now to live my MS, but back then I didn't and that's why I stayed disabled longer. The crutches give me the confidence to walk and that's how I've been for 4 years. Now, the positive things that came out of this for me, after such a negative start, was that I took over from Linda the support officer for people with MS at the Newark NW branch.

L: ah I see so you work closely with people with MS now?

E: Yes I do. And I love it. There are 4 of us who work together and we voluntary run an information centre for people with MS and their families. And it made me be able to talk to people, how to respond to someone who is in the middle of a relapse, I know about my MS now and I can pass on information, or support, because I know how crap it feels when your in those situations. They can ring me and I can help sort it out. I would never say oh I don't know I will try my best to do something. So this is what my job is now. I left my other job because I had the

bad relapse as I was planning to go back so I just didn't bother to be honest. I had more serious things to be thinking about.

L: So you would do this job in a voluntary role now?

E: Yes I would. The other job I had stairs to climb and I couldn't do it. But I don't blame the employers cause they were good with me and they offered me the choice of retirement which I had to do otherwise I could have lost my house and everything. At the time I felt like I'd took the coward's way out but I am ok with it now. I would love to work but because of my finances I manage well on benefits, sick pay and things and I manage to afford the mortgage and because of my health I can't really change that because if it all went wrong again I have no savings now. Where do you live Louise because you'd be welcome to come down to the centre? If I had thought on I could have arranged something whilst you were here in the area.

L: It sounds fantastic all the work you are doing there.

E: Oh it is. I do 3 days a week voluntary and we organise massage, reflexology, physio, talkers, like MS nurses, information officers. I mean we have done so well with funding that this year the national centre refused to give us anymore money! We are hoping to get a website soon. I think the domain name is www.newark.org.uk that sounds about right doesn't it? Watch out for that and you can see what were doing and how we help newly diagnosed etc. In fact yesterday I helped 2 newly diagnosed people with a talk and information and they know that we are there if they need someone. When time has passed and it's sunk in. You know that's what we want to be there for people.

L: Wow you're doing a lot of work. I will watch out for the website.

E: I have made so many new fantastic people since I have been working at the information centre. I have got 2 or 3 really close friend snow, and we go out for lunch or sometimes on a w/e and I am starting to get a social life. I make sure the

kids go off to their dads every other w/e so I can have that space to myself because you need it to then be a good mum.

L: How did you find friends behaved towards you after your diagnosis?

E: People avoided me; people I thought were friends didn't know what to say to me. They say sorry and offer support, but then there gone, kapusch, never to return. Kate, a supposedly good friend of mine, stopped coming to see me once I had been diagnosed with MS. I asked her why (I called her up because I needed friends) and she apologised and said she found it difficult and didn't know what to say to me. She said she would start up again, coming round for a brew like she used to, but I have never seen her since.

E: Actually this is a bit of an awful story but about a year after I last saw her, when she said she was sorry and she was going to start coming round again she died in a motorbike accident...I remember thinking who is the luckiest one of us, you know. I have prioritised myself now. I mean when Kate died I was upset because we weren't seeing each other but I also had felt really bitter towards her. And that went then, which is good because bitterness is an awful thing to carry round you know.

L: That must have been tough for you?

E: It was, yeah, course, yeah, but I moved on and I don't want to carry bitterness with me. I mean, my mum and me, we have an on, off, relationship, always have done, and I do carry, yes, if I'm honest, I do carry bitterness for my mum still, I can't help it, it goes and then comes, and then back again, like waves.

L: Really. So what's your relationship like with your mum now?

E: You see with my mum its always been odd. Since I was a teenager I was never quite right you know. I was always at the doctors being tested for thyroid, as I used to get bad depressions, odd things, which were always seen as being borderline like the thyroid tests were borderline. From a young age, about 16 I was given anti

depressants, I mean lets face it they cure everything! So I`d been taking anti depressants forever really. And I`ve always been a really doer kind of person, my real father had a lot of psychological problems and mum used to worry I was like him. I look back now though and I think my mother should not have let me take anti depressants?

L: Did you tell her this at the time?

E: I`ve always had a real funny relationship with my mum you know. She was always telling people I was lazy, and fat, and that I am always asleep. She has always been critical of me and anything I do and I sometimes think back to when I started with the symptoms and wonder if this was why. You see, my natural dad had mental health problems and when him and my mum divorced when I was a small child she used to identify things about me that were mad like him (laughs).

L: That must have been tough for you?

E: Yes it was, very tough. I think now that I can identify the symptoms of MS from when I was 16, 17, 18, you know from when I had all this shit with my mum really. My mum is one of those mums who just picks. She always has done since I was young. She used to describe me as lazy and make out I couldn`t be bothered to do anything – but now having the MS explains so much, and is such a relief. I`m not mad and I`m not lazy...mum spent lots of years picking at me, pulling me down, but in a way I can`t tell you, it was done through comments, always with a smile, snidely done, she`s clever my mum...I sometimes think that she brought on the MS, I might have got it, I don`t know that, but something makes me feel that she put that on me, with the way she was, cruel to me.

L: So do you feel that your MS was brought on with the stress?

E: I can say hand on heart that, well I got chicken pocks at the same time, about 17, and that floored me, but it was when the tensions between me and my mum, you know the picking, telling me I was like my dad all the time, you know mental, that`s when I got all these aches and pains, I was never the same from then really. I

would say I probably had a slight drink problem when I was about 20, but I managed to get through that and then next minute I was married and having children.

L: Have you always had your mum in your life?

E: The thing was even when I left home my mum would be round saying our Emily, you're always tired sign of depression, go back and see the doctor to sort that out, then next minute she'd be saying pull yourself together, it's all in your mind, you know. And 25 years ago this was the attitude that people had. She wasn't to now that my marriage was failing miserably and I was feeling like shit most of the time. I mean he had affairs with 3 of my so called friends. Always blamed them, you know, for leading him on, whilst I used to sit on the couch getting fatter and fatter. When he left me it was a relief because he was torturing me, you know, because like me mother he would tell me I was mad. I had imagined he was screwing my friend. You know that kind of thing and I don't think anyone deserves that, no matter what you've done, that's just bloody cruel.

L: That must have been a tough time for you Emily?

E: It was, a really tough time, and on top of that I was dealing with these things on my body. You know, the numb patches, the odd sensations, dealing with doctors.

L: Did you find it difficult when the doctor didn't take your symptoms seriously?

E: The most frightening thing was that nobody took me seriously. My body was physically changing (at the time I thought I had had a stroke or something) and the doctor told me just to relax – it made me feel worthless and to think that nobody believed me was horrible. I couldn't use my arm properly for weeks and my shoulder was in pain and I remember thinking well if I drop down dead they will all be eating their words then

L: Yes. Do you feel more comfortable with having MS now?

E: Hmm, well, erm, of course I never know what's happening with my body each day. The MS makes everything unpredictable and some days I get really depressed. It can hurt to be tired, that kind of tiredness that you get with MS and it just grabs you and you can't do anything with it but get in bed. That unpredictability gets me but I manage it much better now...it help so much when you know what it is, I know I have MS now so I can do something with that

L: Have you changed in the way you think about MS? You know, from when you were first diagnosed.

E; Yeah, I have definitely learnt to handle it now, or much better now.

L: Can you give me an example?

E: Yeah, erm, well that first big attack that I told you about when I was just diagnosed was a terrible time. My legs at the time weren't working – they were numb and felt like they weren't there - and I used to stay in bed thinking that because I couldn't feel them I couldn't use them. This would make me cry and feel sorry for myself. I have since discovered though that I can use my legs. I have never had complete feeling come back in them so it was either stay in bed or get myself a stick or chair to help me get about. I have got used to my legs now. If it is dark or my eyes are closed it feels like they aren't there, but if I can see what I'm doing I can use them.

E: What do you think about the future Emily?

E: I don't think about the future really. I've never been the type of person that thinks and plans ahead. When I was diagnosed and I got over the shock of it – because at first I was just glad it wasn't motor neurones - I remember sitting here thinking who the hell will ever want me now. I am overweight, single parent, and now I have MS. It's a lot for someone to take on .

L: So do you tend to focus on the here and now then?

E: I get bad days now because I do have problems every day and I just go with them... I call them my MS days but I can see there is a future worth living for.... I remember thinking it could be worse I could be dead. I do have good things in my life – things that weren't there before. Although I was initially devastated at being diagnosed with MS I think I came to terms with it. I don't think too far ahead if I'm honest and I do get scared. Do you not find doing this research depressing – how does it make you feel?

L: I find it challenging sometimes but I am really enjoying talking to different women about what they have been through. I think that makes it worthwhile, you know, it probably helps me too at some level. Like how you talk to the student nurses, that must help you too?

E: Yeah and I do get a lot out of that.

L: You also mentioned working at the MS centre? What do you do there again?

E: I work at the Newark MS information centre 3 days a week and I get to talk to people who have usually just been diagnosed with MS. I love my work and I'm doing things I would never have done if I had not got the MS so sometimes I think it's just meant to be. Do you know what I mean? I'm not spiritual or anything but I do think things happen for a reason.

L: And does that attitude help you get through the bad days you mentioned before?

E: Oh yeah, it helps, anyway, at least I can get myself back in perspective, I mean I have had worse times in my life.

L: Would you like to tell me about a bad time Emily? (If that's ok with you).

E: I was working nights when I was married for about 4 years, 3 nights a week, living with an inconsiderate husband who would shout up at me constantly. I mean we couldn't afford childcare so I was working 3 nights a week and looking after 2 small kids in the daytime, it was hard going on me, you know, not good I can't

remember being awake at all during that period. On top of that I had quite a stressful marriage and I was very very insecure and nervous and under confident about myself and the way I was with the kids. Everything was just a mish mash of me being tired, I never wanted sex, you know, it got incredibly and utterly stupid. In amongst all of this I was depressed, weight gain was huge and I was just exhausted. And then my mother and my husband would say to be constantly, 'you're always asleep', 'what's wrong with you', in that nagging, miserable way really.

L: I have heard this story so often

E: On top of this he was having affairs with friends I had made through the kids. I would be knackered. On top of this I knew I wasn't lazy or mad – how could I be lazy with all I was doing? It doesn't make sense. I knew there was something physically wrong with me but nobody listened to me. They would blame it on me being weight. And you know I have really healthy blood pressure which I always tell people is not bad for a fat bird. **Laughs.**

L: That sounds like an incredibly challenging time for you. I can't believe you worked nights and they stayed up in the day with small kids, you must have been shattered. How did you do it?

E: The only time I felt well again was when I went through my separation and divorce. **Laughs.** Joking apart it was a relief to be out of it and although I did feel down at times, like you do, you know, that goes with the territory, it did not make me ill. Staying married to a man who lies and cheats was making me ill all the time. I'm not saying he is at fault for the MS but his behaviour was terrible, truly dreadful to me. He must never ever have loved me. He couldn't have done.

L: And this was before you had received a diagnosis of MS?

E: Finding out I had MS explained so much about me, my life, my stresses that it was a relief to have the description to talk about. It doesn't surprise me that I have been so ill. I don't know how I add all that up together, if you will, but it makes sense to me.

L: How do you manage on a daily basis now? Do you think about how you manage?

E: It could be worse I could be married! **Laughs.** If I worry about what's going to happen I could get worried and depressed and I probably wouldn't get out of bed. I know my rights now, I know about MS and I know how to get help and support if I need or choose to have it. I won't let MS beat me. Sometimes it's tough and I admit that sometimes I might go 2 days without a shower because it's too hard, but only I know that. I don't broadcast that to other people so they can start interfering. I don't want my mother showering me – it's as simple as that, you know. Some days I cry, no reason, I just cry, I go to bed, no one knows and I cry away to myself and it gets it all out. The fear, the loneliness, yes cause I am lonely. I do have friends but I don't have anyone to be intimate with, to hold me, make me feel good. And the truth is I probably won't do either. The last relationship I had ended last year. He wouldn't leave his wife like he said he would do – are you shocked?

L: I'm not shocked I was just surprised

E: Yes, because of what I said about my husband. I bet you can't understand how I could do that after I was cheated on so badly.

L: I think life's complex to be honest and I wouldn't judge somebody about their life and things.

E: to be honest, he's married, but only in paper, if you will. His wife leads her own life, and they are together because basically it's too much hassle to split up. I think financially, that's the concern there. I see him about once a week and he rings me in between, and it's nice to know somebody cares about me, that's it really erm. And he talks to me, which is great, you know when someone talks to you properly and is interested and I do ask, I mean, I ask him about my MS and how he feels but he says it doesn't bother him, that he likes me.

L: Do you think there is a future Emily?

E: do you mean with the man...Chris he's called. I don't think like that, as it's too complicated, and then I might tell him I don't want to see him, but I don't want to do that.

L: What about the future Emily?

E: the tiredness gets me, its bad and it hurts, the tiredness hurts. I often think what shall I do with myself. I don't know about the future, I hope that I can carry on, I want to . I would like to build my confidence, Christ everyone thinks I'm confident, I've spent 42 years coming up with this façade of happy go lucky, Emily's fine, you know and I get tired of that. That person people think I am. Then I think is this persona me, is this the real me, but I don't know. Last year I went to talk to 160 people about living with MS and I was ok with it. I have done things I never thought I could do. Before I knew I had the MS I would get diarrhoea if I had to do anything that involved me, just me, like a meeting where I might have to speak. But the MS has given me something, I can do things I never ever thought I could ever do. And that's the truth of it, it really is.

L: You mentioned earlier about having good and bad days. How do you manage those?

E: Today I've had a good day, some days I get very down. Very very down and I just stay put til I can rise out of it. Depression. That's what it is. I don't know if it's part of the MS, or if it's because I have a lot to be pissed of about. That's the golden question. Yes, but I do have good days, mainly, good days, and that's copeable. I have a life now, I have a few friends, the kids are older and more capable, and I have accepted that I have this bloody illness. The bad days, well I do get them, and they are tough but, and it's a big but, I do pull through them at the moment. That's all I can say, I pull through them at the moment.

L: How often would you have a bad day?

E: On a bad day I don't get past the door. I haven't had a proper MS day now for 6 or 7 weeks.

L: And is that a long time for you?

E: Yeah, for me that probably is! Of course I never know what's happening with my body each day. The MS makes everything unpredictable and some days I get really depressed. It can hurt to be tired, that kind of tiredness that you get with MS and it just grabs you and you can't do anything with it but get in bed. That unpredictability gets me but I manage it much better now...it help so much when you know what it is, I know I have MS now so I can do something with that. You know, another thing I wanted to mention though was about the man I have been seeing, yeah, seeing since, well for the past year, the one whose married, I think I wanted to say that it's tough trying to have relationships when your disabled – god I hate that word, but yeah it's true. I mean I don't know where the relationships going. I have known him since I was diagnosed but I'm not sure, why would he want me, I don't work, have earning capabilities, they could end up nursing me in years to come – I have in fact already picked my nursing home so that I am in control of what happens to me.

L: Do you find that difficult?

E: I do, yeah. I mean I am good at being selfish now, I make sure that, I mean, the kids are older now, but I always make sure that a Friday night is mine. But like tonight, the kids are out, so I usually would have maybe, well I could have seen Chris, or chatted on the phone or internet, but you came and I got my adult company for the evening. I chat with my sister, she's just found out she's got cancer, she's 35,

L: Oh God, that's so young,

E: Yeah I know, and in the bigger picture I would rather be diagnosed with what I've got than what she's got. But she says the opposite, on the hand, her attitude is, she says she can get rid of hers, whereas I have MS and I can't get rid of it. Getting back to what you said earlier, just quickly, about the future, I tend not to make plans. If somebody said to me do you want to go on holiday next year, then I would make that kind of plan

L: Yeah yeah

E: but you know, I plan certain things, but I don't plan.

L: Yeah, I can relate to that but that would probably be because that's my personality.

E: I must admit I'm very disappointed with what it's given me because when I was 18 I went out and did lots of things, walking, camping, hiking you know I had big plans **pause** and then I met my husband and it all went pear shaped.

L: Yeah, yeah,

E: and you know, the one plan I did have was when the kids had left home and I could sell the house and move on, and all that I would like to have bought a narrow boat. And done that. And erm, ok, I could still do it now, but you'd need so much bloody money because you would need everything especially adapted so that's by the by, you know, but I don't think about it because I can't do it, so I try not to think of what I can't do

L: yeah, would that make you feel down?

E: Yeah,

L: So you would think about doing that?

E: oh yeah, the guy I'm seeing, things can't develop really there. I really like him, when I met him he chatted to me, I knew the first night I met him, I said to my friend, if ever there was a guy for me it would be him,

L: ah, that's a shame

E: I think he could be my one chance and he thinks his wife is having an affair and I think he's hoping she will leave him, then it takes his decision away. But, you know, I could spend time with him, but you know maybe, maybe not, but in this past year he has given me back that confidence that I had lost, the thing is the day after I was

diagnosed I went out and brought back this lad, I'd known him since school so he wasn't a stranger, and I had sex with him. I needed to feel, you know like I had a sexuality I suppose, so we became, excuse the expression but casual sex friends, buddies whatever you like. This went on for a while and I started to cotton on to the fact that he just came round for sex with me, whilst still taking out other women. I obviously wasn't worthy of that, and my self esteem, I was really overweight then, and my confidence were shattered, and Chris, the man I'm seeing now, has given me that back.

L: Yeah,

E: Yeah, I would like him to be part of my future but I'm not going to harp on to much about the future, if you will.

L: Are you happy in the present?

E: Erm, yes, I mean it could be a lot worse. It could be a lot better, but then I mean I read a book a while ago called the Celestine Prophecy – have you read it?

L: No, no I have heard of it I think

E: You have to read it, you have to read it, its about how coincidences happen, I got MS, then met Chris, erm, so that's a Celestine prophecy, but it really is a clever piece of work, and they say everything happens for a reason basically, I got MS for a reason,

L: Do you get comfort from that?

E: Well erm, yeah, but I don't do comfort in that spiritual way, I'm an atheist, so, but it is if you know what I mean. If I had to be anything it would be a humanist and that works for me.

L: Yeah, yeah, I know what you mean.

E: It has made me look at everything a little bit differently, so, yeah, it works for me. And I always say, when I'm off to see someone whose just been diagnosed, you know, I went to see this 34 year old lad, who had just been told and all he was interested in is knowing if his willy was still going to work. I was like, yes, you know, and I like to give hope, but still tell it like it is, if you know what I mean. I can do that, I can be one person and I would hate it to be like it was when I was diagnosed. I get annoyed with people, you know some people are so selfish, but who am I to say that eh? You know I would be selfish if I could no longer do anything, part of me thinks she could do a little bit more to help herself, she is a bit of a premadonna, but you know she can't do anything; she is totally disabled, so I suppose she's entitled to that.

L: Yeah, yeah,

E: I remember talking to this lady at the hospice, she has secondary progressive, but she says she'd rather have that than relapsing remitting. She says at least you know it's a steady roll down the hill. With relapsing remitting you never know where you are with it, and that's the way you look at it I suppose. And again, like with everybody else with MS, is that you know, I am here today because I can get up and go out, you just adjust to the unknown.

E: Do you not feel like you want to go and have a good cry or a big glass of wine after talking and listening at these interviews?

L: Yeah, but I think I've found that people seem to have similar stories, and I find it really interesting, and it's like a form of therapy at some level for me I think.

Both laugh.

E: Has the interview been useful for you though Louise, have I been alright?

L: It's been fantastic Emily, I can't thank you enough. Just thank-you so much Emily for talking to me. And for being so open and honest. I have learnt so much this evening!

E: Good luck with everything Louise. Please let me know how you get on, and if anything happens with the research, and ring me anytime, you have my number, if you want to clarify anything after this, when you get back home and you think, what did she mean by that!. It's been a pleasure, it really has.

L: Thanks, I will now turn off the tape!

Appendix 10

Iris interview (Name changed to protect her identity)

Interview held at Iris's house

Conducted 05/05/2004

Transcribed by Louise Dawson

L: Louise Dawson, Researcher

I: Iris participant with MS

Pretext

Prior to the interview I rang Iris and talked to her about the consent forms, the interview, and any questions she might have. I also sent her an information sheet to look at prior to the interview. When I arrived at the interview I spoke to Iris about the interview again and we signed the consent form together. I explained again the importance of confidentiality. I discussed with Iris what would happen during the interview and how we could stop the tape at any time to have a break, or finish the interview altogether. Iris said she was comfortable with the information provided and the format of the interview.

L: Well Iris, that's the tape on now, and remember we can stop whenever you want to, just like we discussed, so just let me know if that's what you want – is that ok?

I: That's all fine, Louise, no bother, so what would you like to know first then? (laughs)

L: Thanks Iris. So let's start then.

I: Erm, before we get going are you sure you don't want a drink or anything, I can get you some toast or a biscuit?

L: Thanks Iris, I'm good, the cup we just had was fine, thanks though. So shall we get started then, and remember we can halt at any point, ok, just ask.

I: Ok love, well just ask, ok. I'm ready now to get going so, ask anything you like (laughs)

L: Thanks Iris, Well shall we start with when you first remember experiencing MS then?
When you can first remember having the symptoms?

I: Well, at this point in my life, it does feel like I've had MS forever, you know, it's such a long time for me having the symptoms now, so long, erm, if I really had to say, you know give a date, or age, I would say I'd be about 21 and getting sore eyes n that, vision was not right, just not how it should be, you know, it was frightening like, but, erm, I'd say very early twenties, and if pushed I think when I was late teens I used to get bits of things, the odd feel dizzy, eyes, sometimes, just not right, but it'd be quick, so then you'd forget about it.

L: Is there a specific instance that you can remember?

I: I was about 21 when I used to get sore eyes, right here (places hand on eyelids) and my vision would go blurry, hazy, like. Erm I mean that happened a lot and I was always having aches and pains, odd things that you can't say but they're just there. A bit like a funny toothache, can't describe it unless you've had it yourself. You know one of them things...I did worry a lot about em but whenever I told anyone they'd just say 'Oh Iris, it'll pass, you look fine', so you don't want to bother, so you keep on with it, looking after the kids and cleaning the home, you're looking after everybody else. And you don't have time to keep going on about it so you just try and get on with it. Actually I remember, erm well, it were after I had, I think it were Peter, when I felt terrible, with pains and sore

muscles, and this were when my vision was starting to go wonky as well. I would still be in me twenties then, probably about 24, and I were breastfeeding too, so he must have been under 1, and I just couldn't shift the odd things, you know. This one day, I remember limping about the house, you see, me legs were sore, but I couldn't walk straight, it were me eyes, but me whole head was funny, you know that, and then I tripped up, and I thought bloody hell, I could've had the baby in me arms then, and then it would have been a disaster. So, I asked the doctor about it, you know, what was happening to me, and how I'd had these odd things, and that I'd had some pills but they didn't work (**reference to being prescribed anti-depressants**). He said, well he explained to me really, that having babies takes time to recover from, that me hormones would settle down and that, he give me Valium then I think, I didn't take em though, I was frightened of that stuff, but he tried to help me out, you know..."

L: So you went to the doctors straight away then with your first symptoms?

I: That first time, or it might have been a few times, like, that got me worried, you know, I did what you're supposed to do when not feeling right, I went to see the doctor. In them days, cause you remember I'm 71 now and that's 50 years ago, bloody hell, that's a time isn't it? Anyway, you're asking me what I did when I first got the MS symptoms, well I went to tell the doctor, and he said that it was nothing, probably too busy and all that, I was too busy, not him, he were a nice fella, and he sent me away with some pills, like a valium I think, I were to take it if I felt anxious, and that were it. I think that probably settled me at that point, as I believed it were nothing too serious and then I thought maybe it will just pass away.

L: So, what happened next? Did the symptoms come back?

I: Yes, they did, they never passed away as I'd hoped they would and erm,, and I didn't take the valium things, I think I tried it once but I fell asleep, and I wouldn't, my family. like me mum, at that time, we wouldn't have been big on taking pills, it's the way we were raised so I was nearly more frightened of the pills, if you see what I mean. So, I'd nearly be frightened more of the pills than I would the symptoms, you know that way? Shall I tell you about the lead up to me, kind of, staying away from the doctors?

L: Yes, Iris, if that's ok with you. Please go ahead.

I: So, I'd gone away with these valiums, and didn't take them, and the symptoms kept coming, sore eyes, pains, erm then this one time I had the numbness, all down my left here, this side is still my weakest, always has been since the first numb episode, and I couldn't move it properly, have you had that Louise?

L: Yes, it's a strange sensation I know what you mean, I had that down my right hand side, I was very young then too, so I can understand what you're describing?

I: Yeah, it's horrible isn't it?

L: Yes, and frightening too when you don't know what it is.

I: Now if it ever happens again I've heard cold showers are good for that...I'm not sure why, but I think the cold water at the top of your neck shocks the nervous system, and it can help...just a tip for you there. I know more stuff now about coping and all that, this

information I get it, like, my granddaughters are right keen on looking stuff up for me, and that, and they pass on these tips. They are funny you know, this younger lot, because they use the computers, it's living in different times (laughs).

L: Thanks Iris, it's always good to hear about other people's experiences, thanks for that! So tell me Iris, you had had an attack down the left side, and what happened next?

I: Yeah, so this shocked me and really unsettled me, as you think it must be a stroke or your heart or something, because what else could it be? You think, this is bloody serious, it has to be, I mean, what else would make your arm and side go lifeless, so you think, I've had a stroke, it makes perfect sense really, you're being logical.

L: Yeah, I've heard that explanation a lot when talking to people with MS, because you're trying to understand what's happened, and you imagine it must be a stroke or something, I remember thinking that with my right side.

I: That's true, really, I've heard that a lot now, you know, from others and that, and so I went to the doctor, the same one I'd been to, as there were just one then, not a few of them like there is now, and I showed him my arm and left side, I mean this numbness went right down my back, covered the whole left side of my chest, my head, like exactly half my nose, can you believe it, like a straight line down here (shows with hands), my lips, mouth, but just half on the left and I think the feeling came back just below here (touches rib area), and the same round the back of me, and I was petrified, and thought well when I see him he'll know what to do. I was running in the doctors, like with this funny side, I must have looked a state, and

then I didn't care, I just wanted to see him, I wanted the numbness to go away and I wanted help for my stroke, as that's what I was thinking right at that moment, you know.

L: That must have been very frightening. Did you see the doctor then?

I: Yes I did, and at that time, you can't believe this really, it's almost unbelievable, he checked me, like a feel round where I said it were numb, lifted me arms and all that, then he said to me, 'Iris, I can't find any evidence for a stroke', as when I went in, I'd obviously said to him, I'm worried I've had a stroke, and he said 'I think you should go home and take a rest for a few days, and I think you'll find your arm will feel better, you seem uptight, something like that he said anyway, can you believe that?

L: Yes, I remember I had a similar response with my right side. How did you feel at that point?

I: Oh, it were awful and I was scared and didn't know what to do, I kept thinking, why are these things happening to me, and then the doctor is not believing me. That was the worst because at that time I thought I must have had a stroke, cause I knew my arm felt like it did, even though he's telling me different, so I was waiting to die, or just keel over. I sound dramatic, but at that time, in that very moment, I thought well I'm a ticking clock. I knew it were serious, I didn't know about other things it could be, and your arm, side goes numb, you can't move it properly, you think it's serious, and it is serious, you know, it were scary and I just had to go home and get on with things. Crikey love, I think that me body has always been like this-you know, like, funny and that. At the beginning the doctor

said I was bad with me nerves, and in a way I suppose I was. But I never questioned him, I mean, why would I? He's a doctor.

L: So you just went home and just got on with things?

I: Basically, that's what I did, I did go to the doctors, again, a few times...erm you know when things were bad, don't get me wrong, but then you get to the point where you feel stupid for keep going, and when the message your getting back is that what your having is in your head, then you don't want to keep hearing that, you know someone keep telling you that you're well and that, when you know inside, yourself, that there is something wrong.

L: Can you remember a situation where you felt stupid for going to see the doctor?

I: What you have to remember is I knew the doctor, at that time, since I were a kid, he knew the family, me mum, and sisters, so you don't want to make a show of yourself, and I'd been going a few times, with the sore eyes, funny vision, the odd pain here there everywhere, you know MS, no sense or reason to it, and this was probably like the 3 or 4th time I'd been about this, say over 6 months or so, and he just looked at me, and then he said, well Iris, we have talked about these symptoms before and I did prescribe some pills (he said the name you know I can't remember) and I think it is down to anxiety – are you coping ok with the family, and the children, you know that kind of thing, well hell, he put the fear in me, he did, as I didn't want people thinking I couldn't look after the kids, I think I probably had 1 or 2 at this point.

L: That must have been stressful for you?

I: I were young, so you don't have much confidence and doctors were doctors then, you know, then I think he retired not too long after that, and whenever I were at the doctors for something I'd just mention my symptoms, and that, but nothing ever came of it. Erm, he did retire though not long after that, yes, that's right, yes, he did, I remember that now, but still, I think by then, I were like, just getting used to it, getting used to how I felt, and erm, I probably had a scare from him then didn't mention again to another doctor, you know properly. You see, I did, erm, let me think, just a minute, yes, I did mention it to another doctor, he took over like just temporary, yes, that's right, and I did get a bit of joy out of him, then, I went again, and he had been located somewhere else, you know he were never the proper doctor, kind of caretaking til someone else came in, so he did listen, but no nothing, and no follow up or that.

L: And did you tell anyone else about what you were experiencing with the symptoms?

I: I mentioned it to a couple of me sisters, our Maureen and Hazel, and they were worried about it, like you would be, erm I did mention it to Teddy (my husband) he didn't really pass any remarks unless it affected him, like his tea not being ready, or him having to watch the kids so I could lie down. And I would talk about it often to close friends, people who knew me, and they would notice the things sometimes, so you'd have to say something about it anyway because you'd look daft sometimes, spilling stuff, coffee you make and just being a bit slurry sometimes, those kinds of things. Then I might knock myself and I'd have bruises on my knees, elbows sore, and erm, yeah knocks and bruises, and because of the way Teddy were, he was a bit heavy handed in the early days, not now, and not for many years, my sisters, our Hazel anyway, would hate it, I mean hate it,

because she'd think I were making up stories to cover for him, but it weren't it were me MS, like, and I didn't know it. Teddy, (that's me husband – I said that didn't I already!), at the beginning did say he thought I was imagining it. He used to be terrible when I think about it, he was a real bully back then. Then, you see, it was alright for men to hit women, now I hear it's a bit different. Don't get me wrong he hasn't laid a finger on me for years, and he wouldn't now, but it made my MS worse in the old days when he was rough...I can see you look shocked by that...it were like that then, me own dad hit me mum, and were rough with her, so I didn't see it as being all that bad. Now, I see a different Teddy, who doesn't do that, and hasn't for a lot of years. He changed, and without anyone helping him, just me saying I've had enough.

L: That must have been difficult Iris?

I: When I got the limp, about 20 years ago now, Teddy was a lot nicer to me-in fact he changed then. He's always been a good husband-don't get me wrong, but he started helping more. I think being ill helped us as a married couple(erm, let me think)...I remember exactly the day that Teddy turned it around. I had been bad again with the leg pain and it was starting to be a regular limp, and I was unsteady and dizzy and that. He was his usual bad tempered self when I said to him 'it has to stop. I am getting more ill each day and I won't be able to look after you or the children. Please stop, just stop', and he did. I mean it wasn't overnight or anything but I think it frightened him, me not being able to look after him.but it were a stage, it hasn't been in the marriage now for a lot of years, you see I gave him a chance and he came good, not many can say that, but it's true, he came good, and maybe if I'd not had the MS I mighten have waited for him to change, and that's the truth of the story really, because who would, but I had problems and I wasn't running off anywhere at that time, and

Teddy took his chance to straighten out and be a better man, and he followed through with that, so I can't knock him.

L: That must have been hard Iris, especially having the symptoms and the children?

I: Oh it were, don't get me wrong, I don't condone any violence, and Teddy knows that, but that was then, that's a long time ago now, but it were part of the start of me MS, so that's why I'm telling you, cause it were there, but not now and not for a long time.

L: Ok Iris, Thanks for being so open and honest about your experiences. Did you attend the doctor often then about the symptoms?

I: I went to the doctors for a lot of years, a lot of years before I was looked at properly.

Doctors said it was me hormones and that, so you just take what they give you at first and you don't question. Why would I? In my day women didn't question (not like they do now, it's different now), and the thing is you do have ups and downs with your periods especially when you've had babies. I thought that the things I were getting happened when you'd had a baby, I mean I were young and didn't know any better.

L: How did you feel Iris at that point? Can you remember?

I: I remember feeling bloody annoyed on the one hand, really let down and on my own, even if you do talk to others about it, at that point, when I was younger I did feel on my own, but then in another way, I did cope, you know, I did cope with it all. And another thing was I remember thinking well I can get used to this, now I can, I can get used to all this stuff and

symptoms, which I didn't know then, and that MS was the reason for this. but now I know. I think well, I'm over 70 now and I have coped, and I'm ok, cause really I am too.

L: So how did you come to be diagnosed with MS then?

I: All this time, and still now, I have been at the same doctors, the thing that's changed is the doctors, if you know what I mean. There were a good nurse who were checking my bloods, Evelyn her name was, she retired too now, and she asked me a few questions, and it came up about the symptoms, and she listened. I didn't feel worried to tell her, I was about 47/48 by then, I was going through the change, and that's why I were having my bloods done, the kids were grown up, and I didn't feel stupid I suppose anymore. So all the symptoms, the soreness, the pains and that, which had all got worse over the years, but then I did have a couple of really good years where it went away, but always, always came back, if I ever thought to myself, they gone now, it was like tempting them, and sure enough there they'd be.

L: That must have felt really positive?

I: Oh yeah, really positive at this point. So, the surgery had like 3 doctors by then, it had grown over the years, and I saw this younger doctor, and the nurse had already told him what I'd told her, and so he was ready for me, and he wanted to know about all the years of me having these symptoms, and how often, and like I'm doing with you now, I had to try and remember, and it was foggy in places, like it would be, you know, but I loved the fact it was all coming out and he was listening. And he explained to me that he was referring me to see a neurologist at the hospital for further tests, which I was a bit urgh about when he said it, and I

was like hmmm is there a point to this, you see I'd got myself on an even keel with all the symptoms by then, and it nearly frightened me to shake that up, sort of, like, I've coped for this long now, do I need to investigate this any further, but anyway I did, so I went to the hospital, it was a good few weeks later, maybe even a month or 2, and I was an outpatient at first, then I had a 3 day stay for tests, which had all the kids worried and Teddy of course, and you know, they did the scan, I had electrodes on my head and monitored, erm one of those needles in the spine, which was ok, not as bad as I'd imagined at all, just headachey afterwards. Am I going off here Louise?

L: No Iris, this is all really interesting? So this is how you became diagnosed with MS?

I: Yeah, so I had this stay at the hospital, and then I was told to come back in 4 weeks. I was under Dr Kearney, and I didn't see him, it was one of his crew, as they say, and they were good to me, they explained stuff and that, I was confused a bit, and like I always say, MS has provided me with the chance to be really dizzy and get away with it! Joking apart though, I can't remember the man's name now, I know he was part of Dr Kearney's team, and he were ok, he told me what I needed to know, which was I had MS. He didn't really say much else, although he did say my history shows I have had it a long time, which I obviously new really, that said it was still a shock to me, confusing, because of what I'd been through at the doctors, and what I'd been told for a lot of years, so it did take me a bit of time to get round it, it's like our Hazel said, (me sister) you can cope and adapt to anything, but it helps if you know what you're adjusting too. Hazel reckons I've played a blinder because she says not a lot of people would be able to raise a family in those circumstances, pull it off, all whilst living with a disease that you don't know you have.

L: Hazel has a good point. So was it a shock to get the diagnosis then?

I: It was a shock in a way in the sense that huh? I mean what do you do with it? At first I thought they were saying I had something extra as well as anxiety, then they said it was probably all MS, then some cheeky young doctor said people with MS do get depressed-I said, well they could only get depressed if they knew about it! Joking apart, I was shocked and annoyed because I thought of all the times I'd gone telling about my health, and wanting support and help, and being scared because I thought I was dying, and although MS is bad, you don't die, so I could have handled knowing about it earlier, but I didn't, and I can't change that, and so I had to get me head round it, but it took a while, it didn't happen overnight, I had angry thoughts for a good while, erm, (coughs) Can we stop for a minute Louise please, I'm thinking Ill nip to the toilet and that, maybe ask Teddy to make us a drink?

L: That's no problem; I'll turn the tape off.

L: Right Iris, the tapes back on here. So before we turned off you were telling me about the shock of diagnosis and how it had made you feel.

I: It was because I had accepted that I was an anxious person and that was what was up with me. Teddy would say now that, for a lot of years, he worried that I had had a stroke or something, because he would see that my side was off, or my arm wasn't moving as it should, and he says now that he really thought well the less said the better, as I was up every day and I was surviving, getting on with it, I raised those kids fine, you know and no-one's saying anything to me, so you just get with it, as they say, you move forward.

L: So were you given any information at the hospital when you received the diagnosis of MS?

I: I got a couple of bits, and they gave me the number for the MS Society branch, who I do know now and I like them, and I go to some of their functions. They have a newsletter, it's just local stuff but it keeps you linked in with what's going on. I have made a couple of good pals there as well. Dorothy, I met her through the MS and Olive, I met her too and they are good to chat with. They would be more disabled than me I'd say, in a way they have given up altogether, but they laugh, we laugh, and we chat on the phone if we haven't had the chance to meet up. Erm, now, when was it, erm I rang them, probably about a week or so after the hospital, the local branch, just to talk to someone about the MS and to try and get some information, I know Janet encouraged me to, because she thought it might be helpful to find out a bit more about MS and I think she wanted to know for herself, a part of her was worried it could be hereditary, but now we aren't worried about that, do you?

L: Shakes head.

I: Yeah I think at first all the kids were worried for me, but there was a part of it that was for themselves, which is natural, bless them, and they didn't want to say it out loud, they were concerned shall we say, about the impact on themselves, if they could have it or be a carrier, that kind of thing, and it is a worry for kids too, and then when we rang MS society, someone came round to the house, they were great and so helpful, giving us all the info, they knew everything about MS, and they really settled it down in my kids heads,

and it never put them off having their own families, which is wonderful thing because I enjoy being a grandparent, and so far we have no reports from anyone in the family showing any of the signs for MS, or any of the symptoms I've had over the years, so we all keep our fingers crossed and you keep on hoping for the best, which of course we all do, it's the kind we are. As a family, and now we have 3 generations of us, we are upbeat in the way we think about things, apart from Peter, he can be solemn at times, I did worry for a while that he had a depressive side, a bit just down, and I used to watch him for the MS signs, but I don't now because he is good in himself and fit and healthy, he has run marathons for the MS to raise money, yeah, so generally speaking I am happy with the family and their health.

L: You sound really hopeful Iris.

I: I am very hopeful of life and people, erm I love meeting new people, like yourself, I was looking forward to today, to talking to you, and telling you about my MS story, because it's been an adventure, I suppose you could call it that. I know that even after all the comings and goings over the years; I still think that me getting the MS was how it was going to be, because even though I think it came on early because life was stressful for me at the start, when I first got the symptoms, and I think that's what brought it up to the front, made it come out, life were tough then as I mentioned before, marriage was hard, kids were hard, money was tight, the whole lot, that's how it were, and I'm a strong person, but I think that stuff comes out in you, I believe that, so I think that I pushed myself, or life pushed me, but I would have come out in it anyway.

L: Yes, I hear what you're saying. Iris, do you feel like MS would...

I: Sorry Louise for interrupting but can I've remembered a story I wanted to tell you about.

L: Sure Iris. You go ahead.

I: Well before we started talking about before the diagnosis and I wanted to tell you about when one of the nurses at the doctors mentioned to a friend I was with that I had MS, or it were something like that. I forget the proper details about this, but it happened, I just can't remember exactly when, where, all that detail stuff. My memory gets slow sometimes, you want to start writing things down Louise whilst you're still young an that. (**Laughs - I remembered yer name this time!**). Well one time I were at the nurse clinic, it's attached to the doctor but you see the nurse instead, that kind of thing. The kids were still at home, our Janet was probably about 13 something like that and Cassie, my friend over the way came with me to the nurse cause she were worried you know about what I were getting an that. And this nurse said to her, (Cassie), when I had nipped out to do a water sample, she said to Cassie, they were chatting and Cassie were saying that I get these things all the time and it's not right, and the nurse said something about me having MS but they can't help me and it's best if you just get on with it, and not to tell me as I might go worse. Well Cassie were worried at this as you can imagine, and told me when we'd left about what the nurse said. The thing was she was unsure if she said MS or something else, so we just had a laugh about it, you know, cause she couldn't remember to tell me, the medical name...isn't that terrible? Eh, can you believe that?

L: Yes, yes Iris. Gosh, that must have been confusing at the time, especially when your friend is giving you half a story. How did you cope with that?

I: The weird thing is I didn't even kick up about it, no fuss, no nothing. I look back now and I think why wasn't I in there the next day asking what the hell was going on talking about me to my friend like that and not giving me any information or saying anything to me. Why did I put up with that eh? What was going on with me to say nothing?

L: Does that frustrate you now?

I: It does a bit, but then, I always think well you did what you did and there's a reason for that, there's a reason we do what we do, I always think, erm, like you can't go back with the clock, and you can't change the past either, so I know things I should have done, but that's the wisdom isn't it? That's what I can pass on to the younger ones.

L: One thing I meant to ask you before Iris, do you still see the neurologist regularly?

I: I don't see a neurologist (at all) at the moment. Like, I don't have regular appointments or anything, but maybe I could if I asked, to be honest, maybe I could. I think that it could be a waste but maybe if I'd seen one the whole way along then that would be different, like it might have helped me, cause I spent a lot of this illness not seeing anyone, so then you don't know, do you, what the difference would be if you had...does that make sense?

L: Yes Iris, I hear what you're saying. So you don't see the point in seeing one then?

I: Yes, I think that it's a bit late in the day for me. I went the one time when they diagnosed me, and I don't think I ever went back. What would be the point really? As I

understand it once you've damaged that area on the brain with the MS they can't get that bit better. So my leg can't improve because that bit of me brain is damaged all the time and they can't change that. I read in the Express about MS cures, people getting out of chairs because of these medical people and their inventions but I don't believe that. How could they do that?

L: Would you read a lot about MS then?

I: Just bits I pick up through the news and the papers, or when they run information sessions at the local MS branch. I, erm, hmm, erm, let me think, I have watched a couple of videos about MS, one was from America, a woman there, who was living with it, and it was a story about her life, it were interesting, me and Teddy watched it, Peter brought it for us I think, erm, not sure where he got that now, I wonder, erm, anyway, and I read that book a few years back that Carol one, who worked on the planes, now her story was alright but it were different cause she had loads of money, it were different to how I'd been or how like Dorothy, me and her talked about it, and although we could see similarities with the symptoms, we couldn't get our heads round the other stuff, she had been to private clinics and all that, so it was removed from where we had been with our stuff. But you k now she's younger and you wouldn't begrudge her anything, and you hope she's ok, I've no idea what happened to her, do you know that woman, have you heard about her?

L; Yes I have read her book. I remember thinking similar to you about her, that she was quite privileged with the private healthcare, and I couldn't relate to her experience, the

same as you. So Iris, have you thought about whether you might go to see the neurologist as some point, even if it's for information?

I: Erm, you know Louise, I don't think I'd bother at this point. Erm it'd be a hassle and I'm managing just fine here with Teddy, he cares for me really well I have to say, he came good with all this especially after the diagnosis, that was the most positive thing about getting diagnosed, Teddy took it all on and made up for a lot of stuff, not that he's a bad fella, like I said before it were the way things were, erm, I'm lucky he cares for me so well, he'd do anything now, to help me out. Erm so I don't think I would expect money to be spent curing me now anyway. I have had my life and should be relaxing into whatever time I have left. I don't worry now too much about it – as long as I can have a fag and the odd drink that's the only medicine I need...(laughs)...I mean I will see people, you know at bingo and that, and they say 'oh I read this or I read that about cures for MS' and I know they just being kind because they probably think I need help in that way, but really I am quite happy to get on with it, and that's from the heart, my heart, that's how I feel about it now, I don't need to know about new stuff.

L: You're so positive Iris, you really are. It's lovely to hear your story of your MS, and the way you tell it is just fantastic, I've really enjoyed listening so far. It's great! So really, you're just not bothering with the hospitals anymore?

I: oh it'd be daft trying to sort me out now, I'm too old now, and I want to get on with it. I have to die of something, and the chances are I'll not get much else now, if I'm lucky, so let's make the best of it (laughs).

L: (laughs) You mentioned that Teddy looks after you now if you need support with personal care. Does that work ok? Have you ever tried to get support from the primary care, such as a carer?

I: This one time I had a visit from the social worker; it was when my daughter rang em because she thought I should be able to get support and help. And when she came, she were very young, not that I mind that, and she were dead nice lass, but I thought what the hell does she know about MS... She left me with the form, you know, about the meals help and cleaning, and I ended up throwing it...erm, what use is a long bloody form to me...no-one ever came back to see how I got on, or that, and I mean she were nice lassie, but I never heard again. And she were supposed to be just for disability, and that were her job, to see if you need help, and get you things, but no, I never saw her again. I mean, she could have left by now. And then Teddy does that stuff for me, and if he gets stuck Janet usually gets a call and she'll come over, and she helps out and she doesn't mind as I wouldn't want to be a burden, and she knows that, they all do, but with her being the eldest girl she probably gets called on, but then me and her were close, and she's close with Teddy, so he would naturally call her anyway, she would be the one he would turn to, like, so that's how it is.

L: It sounds like it's all working well anyway Iris. And what do you imagine for the future Iris?

I: I just hope to carry on as I am doing really. See my kids and grand-kids and get on with it. You can't ask for anything more really can you? When I was younger it was all the stress, you know, all the arguing and fighting that goes with bringing up a family. Things

are calmer these days and I have my little treats. Still have the odd fag if I want one and a drop of wine if I feel like it. Yeah, I would like to stay as I am. I'd be happy to be like this, that's what I'm saying.

L: Yes, I can see you are happy Iris, that's for sure!

I: If I was younger I would probably want to tell everyone how bad it is, you know, not being diagnosed with MS and the thought that you're going mad. But back then I could never have done that. Now I don't want to because I want to be happy and just live. I wouldn't want to waste the time I had left on arguing and being miserable. I think I've done enough of that in my life.

L: And how do you feel about the future?

I: Ach, I'm ok about the health stuff, I can live the rest of my days with MS. It's not as scary as you think it is, it's the not knowing that makes the fear, the being scared comes from not knowing why your bodies doing, or why it's doing it. I think if I did go in decline, or Teddy gets unwell, then we'd look at getting someone in to help us, I don't want to go into a home, although I would before the kids had to look after me, I don't want any pressure on them. To be honest though, I've been stable, like this now for a good few years, so I can't imagine I'd be getting worse, to be honest, and I do take it easy.

L: Yes, is there anything else you'd like to tell me Iris, or are you ready to stop now?

I: I think I have told you everything I planned to, you know what I felt were important and that which fitted in with what you were looking at. Erm, you can always ring me up and come again you know if you think there's more stuff to talk about anyway. I am pretty tired now love.

L: That's great and thank-you so much. I'll turn tape off now!

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longitudinal study of multiple sclerosis in south west England (The South West Impact of Multiple Sclerosis Project, SWIMS) 1: protocol and baseline characteristics of cohort”, BMC Neurology 10.

ⁱ Copaxone (please see appendix 1 for BNF description) is a drug prescribed for people with MS and works on the premise that there is a protein missing from the body. Copaxone (please see appendix 1 for BNF description) is the replacement protein therefore slows down or puts in remission, the symptoms and progression of MS. This is discussed further in Chapter 2, section 2.2.

ⁱⁱ Multiple Sclerosis is a debilitating disease and once disability of any part of the body has occurred through scarring of the myelin sheath, at present there is no cure (Halper & Holland, 2011).

ⁱⁱⁱ When it came to collecting the data I was particularly aware of tensions between being a researcher and being a woman with MS. On the one hand I felt an immediate connection to the women because of the commonality of having MS, yet I also recognised the position I was in to be able to conduct this research project and the power I had in shaping and interpreting the data collection. The process of this study aims to link the experiential to knowledge – to understand the social processes that have occurred, or are occurring, for women living with MS

^{iv} This is very important especially when the researcher is involved in subjective research as there is the potential that the researcher could recognise themselves as being in the same situation as the respondents. The researcher should recognise that they potentially gain more from the research experience than the respondents whether it is career progression, privilege or having the ability to conduct a study.

^{vi} Personally I have a lot of voluntary experience in this area and have engaged in discussion at meetings with healthcare workers on this issue. GPs will openly admit that they are not experts on all medical conditions and may only come across two people with MS in their whole careers). Jelinek (2005) also emphasises this point.

^{vii} When I achieved my first piece of research about women with MS (undergraduate dissertation, 2000) I felt empowered that I had transferred part of my lived experience into a knowledge base. I also felt empowered because I had transferred my story, and other women’s stories into the written form. The women in this study showed they had some control over their illness by telling a story that belonged to them.

^{viii} I remember a similar situation with my own understandings with the MS symptoms. I used to get frightened at times by them so I would attach them to certain things – like I was working too hard and not getting enough sleep. I also worked in a factory and I spent a lot of time on packing machines which meant that I spent a lot of time in the same position. I used to think I was experiencing repetitive strain injury and that would make me feel less scared about what was happening.

^{ix} Women's experiences of MS and health-care are also dependant on their particular geographical locations in the UK. The regional politics and disparities of health service distribution disadvantage some women and the economically marginalised. This post-code lottery, underpinned by issues of age, race, ethnicity and class amongst other disadvantages creates an unequal and discriminatory approach to receiving healthcare.