

Understanding Emotional Distress in Multiple Sclerosis: a Qualitative Study.

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Declaration

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Thesis Abstract

This thesis comprises a literature review and a research report. The review considers the relational impact of Multiple Sclerosis (MS). It trials an innovative method of synthesising the literature, exploring the utility of a cognitive analytic stance to understand the patterns of relating observed in the literature. Electronic databases were searched and twenty-eight articles were included in the review. Five key relational patterns were observed: *caring–cared for; intrusive–overwhelmed; ignoring–rejected; over protective–controlled; accepting–supported*. A diagrammatic formulation was developed to illustrate how these patterns may interlink. Results suggest relationships are central in maintaining wellbeing. Suggestions for service intervention and support of people with MS and their families are provided. Despite some limitations, using a cognitive analytic framework to understand the literature was considered to be useful.

The research study reports a qualitative exploration of emotional experiences in MS. Ten women participated in semi-structured interviews that were analysed using Interpretative Phenomenological Analysis. Women also contributed to the analytic process. Three themes emerged from the data: *To be invisible or not, Visibility and disability, and It's out of my control*. All themes demonstrate the unpredictable and changeable journey of living with and adapting to MS. Emotions could be overwhelming at times and the women worked hard to manage them on their own. Service and familial support was highly valued but emotional experiences seemed invisible to others. A more holistic service approach would be valued. Help-seeking for emotional difficulties was partly related to perceptions of emotion severity and coping difficulty.

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I dedicate this thesis to the memory of two very special people who died before the project was completed:

Dad – I’ve got here! Yes you “put a spanner in the works” but I’ve managed and hopefully made you proud. I love you and I miss you.

Paquita – Querida Ecu-mama. Gracias por enseñarme como vivir una vida tan llena de gozo y paz a pesar de tener tanto dolor y dificultades. Te quiero mucho.

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Section 1

Literature Review

**Self and Others in the Context of Multiple Sclerosis: the Relational Impact of a
Chronic Illness. A Review of the Literature Using a Cognitive Analytic
Framework.**

Abstract

Objective. As a neurological condition with an unpredictable course, Multiple Sclerosis (MS) provides a challenge both to those who have the diagnosis and those close to them. This review considers published material that details how relationships may be affected by MS and trials an innovative method of synthesising the literature. It explores the use of a cognitive analytic stance to clarify understanding of patterns of relating (to self and others) observed in the literature.

Methods. Electronic databases were searched for studies relating to MS and relationships. Articles were screened according to inclusion criteria for relevance. Studies were assessed and given quality ratings which resulted in the inclusion of twenty-eight articles in the review.

Results. The literature was organised into five key patterns of relating which take account of perspectives of people with MS as well as family members: *caring–cared for; intrusive–overwhelmed; ignoring–rejected; over protective–controlled; accepting–supported*. A diagrammatic formulation proposes how these may interlink with the emotional impact of MS.

Conclusions. By considering the literature through a cognitive analytic framework, it is posited that greater clarity has been given to the relational impact of MS. Relationships appear to be central in maintaining the wellbeing of the individual and psychological difficulties may stem from the imbalanced caring–cared for role. Services may be able to support people with MS and their families to develop more supportive relationships that enhance wellbeing and coping in the face of a progressive condition. Further investigation of the patterns proposed is needed.

Self and Others in the Context of Multiple Sclerosis: the Relational Impact of a Chronic Illness. A Review of the Literature Using a Cognitive Analytic Framework.

Multiple Sclerosis (MS) affects approximately 100,000 people in the UK (Thomas, Williams, Williams, & Hall, 2009). The majority of people are diagnosed between the ages of 20 and 40. MS is a neurological condition, in which it is believed that the immune system attacks the myelin sheath that surrounds nerves. Essentially any part of the central nervous system can be affected meaning a variety of symptoms can be experienced: loss of feeling in limbs, impaired mobility, bladder and bowel dysfunction, visual impairment, fatigue, tremors, pain, sexual dysfunction and loss of cognitive functioning. Symptoms vary between individuals but fatigue is experienced by approximately 75% of people with MS (pwMS) and is often cited as one of the most frustrating and disabling symptoms (Holland & Madonna, 2005). As well as causing unpredictable physical deterioration, MS is associated with emotional difficulties and there is a high incidence of depression and anxiety, with suggested lifetime prevalence of 50% and 36% respectively (Sollom & Kneebone, 2007; Korostil & Feinstein, 2007).

MS is a chronic illness with a complex presentation, particularly as each person experiences it differently. There are four types: Benign, Relapsing-Remitting, Secondary Progressive and Primary Progressive. Those with Benign MS experience no or minimal disability. Approximately 85% of people are diagnosed with Relapsing-Remitting MS which is characterised by “relapses” – sudden appearances of symptoms followed by periods of partial or complete return to prior functioning. This form of MS occurs more frequently in women. Sixty-five percent of those with Relapsing-Remitting MS go on to develop Secondary Progressive MS, where the level of disability and impairment steadily increases. Primary Progressive MS affects 10-15% of those diagnosed and is characterised by a gradual worsening of symptoms over time with no

return to prior functioning. The speed of this progression varies from person-to-person (all figures from MS Society WebPages). Even if two people have the same MS type, it is unlikely they will experience the same symptoms in the same way. This makes MS an unpredictable and bewildering illness for the individual and their family.

Various models have been proposed to explain *illness behaviours*, that is, how individuals respond to and cope with illness and the differences in psychosocial outcome. Most models focus on the individual but chronic illness impacts on the lives of family members too in a variety of ways (e.g. Bogosian, Moss-Morris & Hadwin, 2010; Lim & Zebrack, 2004). One model that takes a familial relational perspective of the impact of illness and disability is Rolland's (1999) *Family Systems-Illness Model*. The model illustrates how three dimensions of factors influence family coping when faced with the challenge of an ill family member. First, chronic conditions can be grouped into '*psychosocial illness types*' according to their biology and associated patterns. Illness patterns vary according to onset, course, outcome, incapacitation and level of uncertainty regarding the illness trajectory (Rolland, 1999, p. 244). As a result of this pattern variation, illnesses impose distinct psychosocial demands for the patient and their family. The second dimension relates to issues of time and individual and family life cycles. The impact of illness is not static, and different demands are made of families during different life stages and illness phases (crisis, chronic and terminal). Finally key family system variables influence family coping such as how an illness is perceived.

Rolland (1999) noted that whilst illness presence may be an opportunity for family growth, there is a risk of distance and deterioration in relationships. This is thought to be especially true when a parent develops a chronic illness during the childrearing phase, the life stage when MS most commonly starts. Dunn (1998) conceptualises this stage as the "prime" of life. Whilst childrearing may be a key task,

people are also fully involved in developing careers and making their mark on the world. The appearance of a chronic unpredictable and progressive condition is unexpected and occurs “off-time” (Rolland, 1999); diagnosis often comes as a shock. MS symptoms can bring a halt or severe disruption to the expected sequence of life events and associated relational ‘tasks.’ For example, symptoms such as fatigue can make parenting difficult (Deatrick, Brennan & Cameron, 1998).

Unpredictability and changeability in severity, visibility and presence of symptoms makes MS a demanding disease for pwMS and their loved ones. Lyons and Meade (1995) discussed the challenges mothers with MS face in maintaining relationships. Challenges included symptom unpredictability, a lack of shared understanding of illness experience with others, and difficulties managing gaps between expected and actual ‘performance’ of family roles. Yet MS does not only make family life difficult, it causes difficulties in wider social spheres too. As disability increases, involvement in social activities and hobbies reduces (Stenager, Knudsen, & Jensen, 1991). With increasing disability it becomes harder to live up to self and family expectations which increase psychosocial strain (Stenager et al., 1991).

Relationship changes with self and others are repeatedly highlighted in the literature as central to the experience of MS (Bogosian, Moss-Morris, Yardley & Dennison, 2009; Bowen, MacLehose, & Beaumont, 2011; Grytten & Måseide, 2006; Irvine, Davidson, Hoy & Lowe-Strong, 2009). Whilst some reviews of the literature regarding the relational impact of MS have been published (Bogosian et al., 2010; Kouzoupis, Paparrigopoulos, Soldatos, & Papadimitriou, 2010), none draw together the various relationship spheres (i.e. partner, child, wider social circles). This review provides an overview of existing literature regarding the impact of MS on the relationships of pwMS, with themselves, loved ones, and wider society. It will take a cognitive analytic stance (Ryle, 1995) in order to highlight themes across these

relationship spheres. MS imposes relational changes therefore it is useful to explore organising a literature review using a therapeutic framework which prioritises understanding relationships. The following section briefly outlines cognitive analytic theory to explore its utility in this literature review.

Validity of using CAT

Cognitive Analytic Therapy (CAT, Ryle, 1995) is a form of psychotherapy concerned with understanding relationships, in particular the roles people play within them. CAT theory proposes that from birth we are learning who we are in the context of our relationships (Ryle, 1995). The infant's relationship with their caregiver becomes a template for subsequent relationships. As that primary relationship develops the infant learns how others behave and how s/he feels in response. For example, when a mother attends sensitively to her infant when the infant is distressed, the child learns that s/he is *cared for* and that the mother is *caring*. However, when a mother ignores the distress of her infant, s/he feels *neglected* in relation to mother being *ignoring and neglecting*. In experiencing this, the child learns both sides of the relational interaction (child and parent positions) and develops a repertoire of *reciprocal roles* (Ryle, 1995). Based on our repertoire we learn to anticipate certain behaviours from others, sometimes unconsciously calling others to relate in certain ways, and we also relate to ourselves in ways in keeping with learnt reciprocal roles. The repertoire may include healthy as well as maladaptive roles. As adults, reciprocal roles will be enacted in close as well as broader relationships (i.e. interactions with work colleagues or health professionals).

CAT can be applied to a wide range of conditions (Ryle & Kerr, 2002) including long-term health conditions. CAT has been used to consider and address relational issues connected to regime adherence (e.g. Chapman, Walker, Cluley & Fabbri, 2000; Fosbury, Bosley, Ryle, Sonksen & Judd, 1997; Walsh, Hagan & Gamsu, 2000).

Emerging research has investigated its use with Medically Unexplained Symptoms

(Jenaway, 2011) and with people who have experienced brain injury (Rice-Varian, 2011). CAT is also used outside of the therapy room, for example as a method of consultation to staff teams (e.g. Carradice, 2004; Dunn & Parry, 1997). CAT aims to help develop awareness of patterns of relating to self and others. Awareness of patterns is the first step towards revising unhelpful ones.

As the literature was examined it became apparent that there were regular patterns of relational difficulties, which mirror CAT reciprocal roles, embedded in the experiences described by pwMS and their family members. Conceptualising the relationships of pwMS using CAT may be helpful as it clarifies and draws attention to the experience. Since families have a role to play in supporting adjustment to chronic illness (see Fisher & Weihs, 2000, for a brief review) developing an understanding of common relationship patterns may be useful. This understanding may provide a platform for considering useful interventions to support pwMS and their families. The review has two aims: (1) to develop understanding of the relational impact of MS and (2) to ascertain whether CAT is a helpful framework to understand the literature.

Method

Search strategy

Database searches were carried out on Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations with Ovid MEDLINE(R) 1948 to Present, Web of Science (WoS), PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed and International Bibliography of the Social Sciences (IBSS) to identify relevant studies on pwMS and their relationships. Articles were searched for from when each database begins to April 2012. Relevant articles were also drawn from reference lists or the “Related Citations” function on PubMed.

The following terms were combined for searching with a limit of “English language only” where possible:

“Multiple Sclerosis”

AND (relationships OR impact)

AND (family OR spouse OR identity OR social support)

Exclusion criteria

- medical articles / case studies / book chapters / non English language
- paediatric MS
- focus on mechanisms of relationship impact rather than on the nature of it

Figure 1 illustrates the search strategy and screening process.

Quality assessment

The quality of the articles was considered using guidelines from Bogosian et al. (2010), adjusted to be relevant to the current review. Articles were assigned ratings of good (G), medium (M) or poor (P) quality based on a total score for the presence of certain criteria (see Appendix A). Quantitative studies satisfying 9-11 of the criteria were classified as good, 6-8 as medium quality and those satisfying less than 6 as poor. Similarly for qualitative studies, a score of 7-9 gave a classification of good quality, 4-6 as medium, and less than 4 as poor. One qualitative study was excluded due to poor quality (Miles, 1979).

Given the different epistemological positions inherent in qualitative and quantitative methodologies, studies were judged for quality using separate rating scales. Methods differ epistemologically in the prioritisation of subjectivity, for example phenomenological or constructivist approaches value meaning whereas positivist empirical research seeks objective ‘truths’. Qualitative and quantitative studies were both included as each contributes to develop understanding of the topic under review.

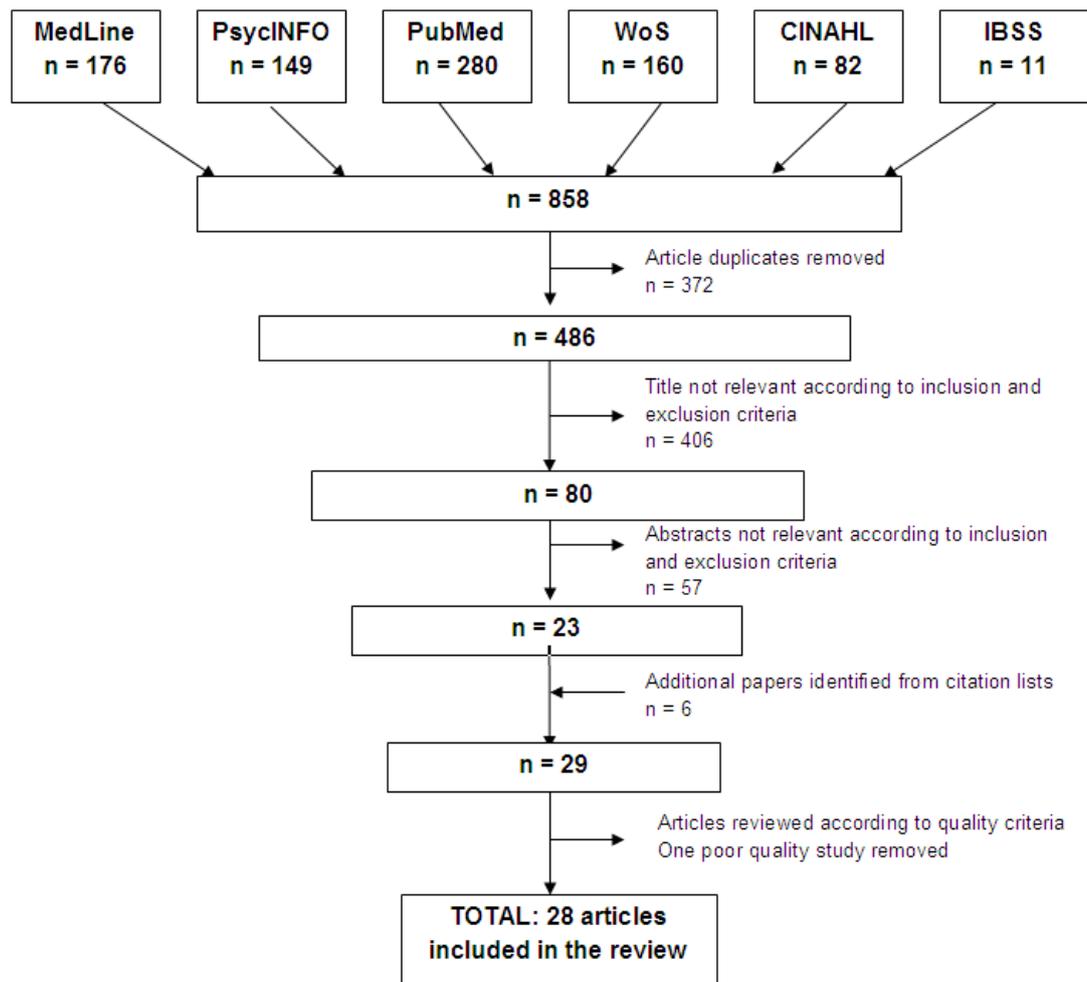


Figure 1. Flow diagram illustrating article selection

Process of data synthesis

Given the CAT framework each article was analysed for CAT-based processes i.e. for information regarding self in relation to others. The researcher noted words that were used to describe: the nature of relationships, how individuals were left feeling by others and how others were experienced as behaving. Initially a large number of relational role words were generated, through a process of refinement these names were synthesised to a set of overarching roles that captured the essence of the relationships described. These roles were ‘verified’ by checking they were grounded in and evidenced by article data.

Results

Study Quality

Eighteen studies were classified as good quality and ten as medium quality. Generally sample sizes appropriately reflected the study purpose and the methodology chosen. For example, most interview-based studies included between 8-15 participants (total range 6 to 49) and survey samples ranged between 101 to 920 participants. Focus group sizes varied between 3 and 12 participants. It was not always clear whether focus group size was appropriate to study aims, for example DesRosier, Catanzaro and Piller (1992) did not justify or discuss the size difference in their two focus groups. The majority of qualitative studies clearly stated the method of analysis (n = 21) which was appropriate to aims, however, further methodological detail was not always provided. Issues of reflexivity and/or rigour or “validation” of themes were not always considered or reported. However, in line with good practice for publishing qualitative research (Elliot, Fischer & Rennie, 1999) many studies made some effort to clearly ‘situate’ the sample by providing contextual and demographic information.

MS as a Relational Process

The literature concerning relationships between pwMS and others (i.e. partners, children, wider family, friends, acquaintances, professional relationships, strangers and society as a whole) was considered. Table 1 illustrates the studies included in this review according to their sample group, methodological grouping and quality rating (for further detail see Appendix B).

Table 1

Studies that report relational aspects of living with MS

Participants	Qualitative	Quantitative
PwMS ^a	Dyck (1995) M ^b Irvine, Davidson, Hoy & Lowe-Strong, (2009) G ^c	Green & Todd (2008) G McCabe, McDonald, Deeks, Vowels, & Cobain (1996) G

	Koch, Kralik, & Eastwood (2002) G	Özdemir & Aşiret (2011) M
	Kralik, Koch, & Eastwood (2003) G	
	Malcomson, Lowe-Strong, & Dunwoody (2008) G	
	Olsson, Lexell, & Söderberg (2005) M	
	Olsson, Lexell, & Söderberg (2008) G	
	Olsson, Skär, & Söderberg (2011) G	
	Payne & McPherson (2010) G	
	Reynolds & Prior (2003) G	
Partners	Bogosian, Moss-Morris, Yardley & Dennison (2009) G	
	Cheung & Hocking (2004) G	
	Courts, Newton, & McNeal (2005) G	
	DesRosier, Catanzaro, & Piller (1992) M	
	Mutch (2010) G	
Children of pwMS	Bogosian, Moss-Morris, Bishop, & Hadwin (2011) G	
	Turpin, Leech, & Hackenberg (2008) M	
Relatives	Bowen, MacLehose, & Beaumont (2011) G	
Couple experiences	Boeije, Duijnsteet & Grypdonck (2003) G	
	Esmail, Munro, & Gibson (2007) M	
	Esmail, Huang, Lee, & Maruska (2010) M	
PwMS and relatives	Edmonds, Vivat, Burman, Silber, & Higginson (2007a & b) G	Hakim et al. (2000) M
	Grytten & Måseide (2006) M	
	Power (1985) M	

^aPeople with MS, ^bM = Medium Quality, ^cG= Good Quality

As MS is a progressive condition, once a diagnosis is received families know that significant changes are a possibility. Yet due to the unpredictable nature of the disease, what the impact of symptoms will be is unknown and this is challenging (e.g. Cheung & Hocking, 2004). When the health status of one partner significantly alters adjustments are necessary within relationships; roles need to be re-negotiated (e.g. Esmail, Munro, & Gibson, 2007; Esmail, Huang, Lee, & Maruska, 2010; Payne &

McPherson, 2010). Tensions may arise as a result of dependency issues (Dyck, 1995; Edmonds, Vivat, Burman, Silber, & Higginson, 2007a; Green & Todd, 2008; Irvine et al., 2009; Reynolds & Prior, 2003). McCabe, McDonald, Deeks, Vowels and Cobain (1996) investigated the perceived impact of MS on romantic relationships. One third of respondents reported a relationship breakdown or greater distance from their partner, another third felt their relationship was closer and the final third believed nothing had changed. A differential impact is corroborated by qualitative studies. Some spouses report feeling their relationship is stronger as a result of MS (Courts, Newton & McNeal, 2005), others have stated the relationship is hard but they have a sense of marital loyalty (Boeije, Duijnste & Grypdonck, 2003). Some partners have admitted contemplating divorce, questioning why they continue with the relationship (Cheung & Hocking, 2004). One suggestion for this differential impact is relationship quality before MS (Power, 1985) and how the relationship is perceived (McCabe et al., 1996).

The nature of MS means it creates a need for social support over a long, and uncertain, trajectory (Gulick, 1994), but pwMS seem to have “shrinking social and geographical worlds” (Dyck, 1995, p. 318). Dyck observed a reduced interaction with the world in general as the home became the “primary activity space.” She noted that women tried to take control over this (by moving closer to amenities if possible) but it could have other negative consequences (moving away from friends). It is widely agreed that social support plays a key role in coping whether one has a chronic illness or not but the physical symptoms of MS impact on people’s ability to take part in social activities. Hakim et al. (2000) noted that pwMS withdrew from social activities and that it was common to have a “shrinking circle of friends.” Poor mobility was the cause of stopping visiting friends and family for one in four of their respondents. As disability increases, social activity declines (e.g. Hakim et al., 2000). MS impacts on employment, and employment status is associated with disease severity (Dyck, 1995; Özdemir &

Aşiret, 2011). Although pwMS try to find ways to manage work, such as reducing hours, adjusting roles or changing jobs, they may have to retire early due to symptoms (e.g. Hakim et al., 2000; Malcomson, Lowe-Strong, & Dunwoody, 2008; Reynolds & Prior, 2003). Loss of employment has multiple consequences for pwMS and their families and causes pwMS to question their role in society, their self-worth and identity (Irvine et al., 2009; Malcomson et al., 2008; Reynolds & Prior, 2003). As the landscape of life alters, it appears family often becomes the main source of support.

Common Reciprocal Roles in MS

This section highlights the common relational patterns, here called reciprocal roles, identified in the literature. By organising the literature using CAT it is hoped a clearer understanding of MS' relational impact will be developed. Reciprocal roles emerged from the descriptions of relational experiences provided within the articles. Some roles were referred to explicitly (e.g. caring–cared for), whereas others were more implicit. In the latter case, it was often one side of the reciprocal role that was noted, how others behave or how the “done to” person felt. The overarching roles observed in the literature are: *caring–cared for*, *intrusive–overwhelmed*, *ignoring–rejected*, *over protective–controlled* and *accepting–supported*. Perspectives of pwMS as well as family members are reported. CAT understands that relational patterns are played out in intimate as well as wider relationships so both will be discussed.

Caring–cared for: changing relationships. A key change in relationships noted by pwMS and family members is a shift in the ‘caring-cared for’ role. This has been noted by several studies: shifts from lover to carer (Esmail et al., 2010; Green & Todd, 2008; Irvine et al., 2009; Koch, Kralik, & Eastwood, 2002) or the possibility of going from parent/care provider to cared for by children (Reynolds & Prior, 2003; Payne & McPherson, 2010). In romantic relationships the role has been found to become unequal, changing from both partners offering and receiving care to one being

the care provider and the other “cared for”. This relational imbalance can be challenging for partners (e.g. Boeije et al., 2003) and pwMS can feel a burden to others (Esmail et al., 2007).

Independence from partners and others was raised by pwMS as an important issue in several studies (Dyck, 1995; Edmonds et al., 2007a; Green & Todd, 2008; Irvine et al., 2009; Reynolds & Prior, 2003) and relationship strain may arise as a result of changes in independence. PwMS can resent being cared for and having to be dependent on others (Irvine et al., 2009) particularly if the care given to them feels overbearing. By contrast, asking for and letting others help has also been described proactively as a choice “to take part in life” (Olsson, Lexell, & Söderberg, 2008, p. 423). Due to the progressive nature of MS, changes in roles often require significant adjustment both within the home and employment. These actual or anticipated changes are associated with a range of different emotions such as worry, frustration, anger, guilt and shame for both the pwMS (e.g. Olsson et al., 2008) and the ‘caregiver’ (Bogosian et al., 2009; Cheung & Hocking, 2004; DesRosier et al., 1992). MS, like other chronic illnesses (e.g. rheumatoid arthritis: Bury, 1982) appears to raise issues of dependency and elicits an imbalanced version of the “caring–cared for” reciprocal role. The literature suggests that pwMS and loved ones respond to the challenges of this change in several ways: feel overwhelmed, ignore MS, feel controlled by changes or try to accept and work with MS.

Intrusive – overwhelmed. Both pwMS and their loved ones report feeling overwhelmed by MS and its consequences e.g. “I want to have our relationship for just us” (Esmail et al., 2010, p. 19). MS symptoms can be intrusive and challenging for pwMS as well as for friends and family (Reynolds & Prior, 2003).

Women have reported feeling like MS has “captured” their body, which becomes untrustworthy and unreliable (Olsson et al., 2008). The experience of

symptoms can feel like an attack to the self as one can no longer complete tasks or perform roles that helped form identity. Women have reported feeling powerless and overwhelmed in the face of MS and its control of their body (Olsson et al., 2008).

Fatigue is a real challenge and social events have to be planned to manage symptoms (Malcomson et al., 2008). Fatigue means not being able to fulfil duties and limits participation in family activities leaving pwMS feeling like the whole family suffers (Olsson, Lexell & Söderberg, 2005).

Conscious efforts are made to avoid adding pressure to loved ones, pwMS do what they can to help whenever possible (Boeije et al., 2003; Payne & McPherson, 2010) yet the nature of symptoms means that pwMS have to rely on others. Sometimes partners feel that pwMS become self-focused or demanding which means their own needs become side-lined (Boeije et al., 2003; Mutch, 2010). Almost half of Edmonds et al. (2007a) sample discussed independence. Individuals who were extremely dependent on others due to their level of disability found it most difficult e.g. “It’s infuriating having to rely on other people” (p. 104). At times assistance from services is necessary, and for pwMS and their families this intrusion into their personal space can be difficult (Bowen et al., 2011; Dyck, 1995; Olsson et al., 2008).

Parents also worry about the impact of MS on their children. MS poses “an ever present threat of turning partners and children into caregivers” (Reynolds & Prior, 2003, p. 1236). Green and Todd (2008) found that 55.5% of respondents felt their MS impacted upon their children. Qualitative responses revealed parents felt this was in terms of their child’s education (their ability to concentrate or their future ambitions) and their wellbeing. Payne and McPherson (2010) discovered that making the decision to become a mother was not taken lightly, it involved seriously considering whether others could provide support. Mothers have to think of creative solutions to manage the intrusiveness of symptoms and report a desire to carry on “as normal” to avoid MS

impacting family life. However, there appears to be a tension between needing to conserve energy and look after one's own health with wanting to be an 'ideal mother' (Payne & McPherson, 2010). When MS does intrude on women's ability to be a 'good mother', it can be devastating (Reynolds & Prior, 2003).

One key theme emerging from two focus groups of female spousal carers of housebound husbands was the need for space (DesRosier et al., 1992). The constant proximity of their husbands and their needs could be overwhelming and the women felt strategies had to be found to maintain the relationship. Social support was important but for many it felt "out of reach" due to being unable to leave the home. MS overwhelmed their lives and life felt like a "persistent struggle." It seems that close family may also experience loss in their support network as a result of MS intruding. Female partners have reported feeling they have lost friends as MS symptoms of their partner have increased (Esmail et al., 2010). Courts et al. (2005) reported that all their participants seemed to suffer a great deal in silence and longed for a space to be heard.

MS can be experienced as an intruder by partners (e.g. Courts et al., 2005; Esmail et al., 2010) who can feel they have lost control over their lives. MS dictates social lives particularly as activities have to be planned due to physical symptoms, or do not happen at all as pwMS sometimes avoid meeting with others (Bogosian et al. 2009). Courts et al. (2005) noted that MS causes role reversals and forces changes that are uncomfortable, causing arguments where previously marriages were harmonious. At the same time MS is a source of worry and anxiety for partners (Bogosian et al., 2009; Cheung & Hocking, 2004; Mutch, 2010), children (Turpin, Leech & Hackenberg, 2008) and other relatives (Bowen et al., 2011). Family members can constantly worry about the immediate and long-term health of pwMS. In an effort to avoid overwhelming their loved one, some partners report sharing their own feelings and problems less (Bogosian et al., 2009). Sometimes children can feel overwhelmed by increased responsibilities.

These extra jobs can tire children out and interfere with peer relationships (Turpin et al., 2008).

Ignoring–rejected. As noted above MS can be overwhelming for a variety of reasons, sometimes the relational responses of others to feeling overwhelmed leaves pwMS feeling rejected. Conversely the behaviour of pwMS can sometimes leave others feeling rejected. The literature suggests that both pwMS and family members can feel that others do not understand or acknowledge their experiences.

Children have reported feeling resentment towards their MS parent due to having to take on extra responsibilities, although they report guilt for feeling that way (Turpin et al., 2008). Responses from family to changes in abilities can feel hostile or unkind (e.g. Kralik, Koch & Eastwood, 2003). Although outright ‘rejection’ by family was rarely reported, a sense of being misunderstood, ignored or left out can be common. When participation in activities becomes limited due to symptoms, pwMS can feel “left behind” and separated from their loved ones (Olsson et al., 2008). Activities that were once shared can no longer be enjoyed together and there can be a sense of loss at being unable to participate. As Green and Todd (2008) noted, it is not just the logistics of organising and planning trips that influence social involvement but the attitudes of others as well.

It has been noted that MS impacts sexual relationships (see Schmidt, Hofmann, Niederwieser, Kapfhammer & Bonelli, 2005 for a review). Women have reported partners do not understand their experience of sex in the context of MS (e.g. Esmail et al., 2007), which can cause a barrier in the relationship. A lack of understanding and sense of rejection coming from pwMS can be experienced by partners as well. For example, the female partners of men with MS (Esmail et al., 2010) reported feeling discouraged by the reduction in sexual activity, leading them to question their own attractiveness. Some men in this study reported asking their partners to leave following

MS diagnosis. So whilst pwMS can feel misunderstood and rejected, partners can also feel this way.

In the wider context, loved ones can feel that friends and family do not understand the nature of the illness nor recognise or understand what they are going through (Bogosian et al., 2009; Bowen et al., 2011; Courts et al., 2005). Young people reported friends, family and teachers could be experienced as unhelpful when they did not listen or understand but minimised their experiences (Bogosian, Moss-Morris, Bishop, & Hadwin, 2011). Several studies have revealed that pwMS and their families believe others lack awareness and should be more informed about MS and its impact (e.g. Courts et al., 2005; Green & Todd, 2008). Yet a family can sometimes deny or ignore MS's existence in their loved one and/or its impact (e.g. Özdemir & Aşiret, 2011). This is especially difficult as some symptoms are 'invisible' but debilitating like fatigue. Others can be less understanding when symptoms are 'hidden' (e.g. Green & Todd, 2008). Grytten and Måseide (2006, p. 200) noted how close others refusal to acknowledge MS is a "violation of self" which leaves pwMS feeling invalidated. Olsson, Skär and Söderberg's (2011) participants felt others did not show sufficient understanding and did not want to talk about the illness. Denial or incomplete acknowledgement of an individual's perspective and emotions can cause distance in relationships.

PwMS can experience many changes in relationships and some have reported that old friendships die, friends stop calling (e.g. Koch et al., 2002; Olsson et al., 2008). Loved ones can also have a similar experience of friendships "drifting" and need to find new friends or reduce their social circle (Courts et al., 2005). Women with MS in Olsson et al.'s (2008) study reported feeling left out socially and unequal. They felt like a "failure" and believed others saw them as "changed." These women felt they would be avoided or ignored which left them feeling angry, frustrated and hurt. Olsson

et al. noted that for women the bodily changes caused by MS, particularly when they are visible to others, meant that dignity could be ‘violated’ and they were “met in a different way.” Relationships with friends or strangers can be difficult for pwMS and it appears pwMS behaved in ways to minimise the possibility of rejection. PwMS often reported a reluctance to disclose diagnosis; however, disclosure to strangers could be useful when disability is invisible e.g. justifying having a seat on a bus (Grytten & Måseide, 2006). In this way pwMS pre-empted possibilities that people would not understand MS. Partners have noticed reluctance in pwMS to be with others and a general avoidance of going outside (Bogosian et al., 2009). Bogosian et al. (2009) noted several reasons for this: low mood, not wanting to use walking aids or a fear of possible accidents that would reveal disability. Half of Özdemir and Aşiret’s (2011) participants reported feeling uncomfortable socially. Participants reported feeling anxious, insecure, jealous, ashamed and worthless. Studies have also noted there are physical barriers to engaging in social activities such as poor wheelchair access (Courts et al., 2005; Özdemir & Aşiret, 2011; Reynolds & Prior, 2003). It seems society as a whole ‘ignores’ MS as it does not understand the needs of pwMS. Irvine et al. (2009) reported their participants felt they were “always apologising” for bumping into people. There was consensus that generally others seemed uncomfortable or embarrassed in their presence. Reynolds and Prior (2003) identified social discrimination and stigmatization as common features of living with MS, and noted that others sometimes related to the disability instead of the person. PwMS have been left feeling unimportant, under scrutiny and disbelieved in interactions with others (Olsson et al., 2011).

PwMS can feel rejected by a society that values everyone contributing.

Participants have reported feeling like they do not have the same value as others, that they have lost ‘normal’ adult status (Olsson et al., 2008; Reynolds & Prior, 2003). They feel shut out, like there is “no room for them in a healthy society” (Olsson et al., 2011,

p. 5772). This sense of societal rejection is not only noted by pwMS. In Bogosian et al. (2011) adolescents reported frustration with how others treated their parent (staring, patronising, completely ignoring) and the lack of awareness shown by people.

PwMS can feel like they have to “fight for everything” in relation to accessing care and services (Edmonds et al., 2007b). Gaining access to information is important but pwMS and carers can feel deserted, unsupported and “fobbed off” by health professionals (Edmonds et al., 2007b; Malcomson et al., 2008; Olsson et al., 2008; Olsson et al., 2011). This feeling is exacerbated by staff changes, service inconsistency and inflexibility (e.g. Cheung & Hocking, 2004; Edmonds et al., 2007b). Although pwMS may have little confidence in medical professionals, they feel they must see them due to needing information (Olsson et al., 2008) although some have reported feeling left with many unanswered questions (Bowen et al., 2011). Family members have reported that health and social care staff have lacked understanding or empathy (Cheung & Hocking, 2004) and been “useless” or poorly trained in dealing with MS (Bogosian et al., 2009). This has left spouses feeling worried, anxious and frustrated about requesting support from services (Cheung & Hocking, 2004).

Overprotective – controlled. MS can become overemphasised and family members can be experienced by pwMS as overprotective. It appears this is either family’s misguided attempt to be supportive or a method for managing anxiety about the condition. When family behave in this way, pwMS can feel controlled or minimised and may respond by withdrawing from others.

Grytten and Måseide’s (2006) exploration of the experience of stigma in MS using a grounded theory approach revealed two processes, one of which was overemphasising. When MS is overemphasised by family members, pwMS reported feeling more ill (see also Olsson et al., 2011). Several studies touched on a sense of infantilisation; pwMS were not given any responsibility and expectations were low.

Feeling pitied and seen as a child has also been noted (Olsson et al., 2008). Over involvement of family could lead pwMS to withdraw which resulted in isolation (Grytten & Måseide, 2006). Courts et al. (2005) interviewed partners of pwMS and found that partners desired to be supportive but recognised they could be overprotective at times and hypervigilant to difficulties. Partners were considered to be vital for support (physical, emotional, financial) by pwMS but participants in Irvine et al. (2009) noted that the development of dependency upon partners could cause relationship tension. PwMS believed their partners did not like watching them struggle with tasks and would intervene prematurely. PwMS however, wanted to strive to maintain independence, reporting that a sense of accomplishment was helpful even if tasks took twice as long (Irvine et al., 2009).

Accepting – supported. Another response to the challenges that MS presents to pwMS and their family is that of acceptance. PwMS have expressed a need to work through a process of acceptance of MS.

Acceptance appears not to be a reluctant giving in to symptoms but is associated with realism about what can be achieved, of living with MS whilst holding a sense of fighting it and keeping life as normal as possible (e.g. Esmail et al., 2007; Olsson et al., 2008). Initially self-esteem and confidence may be affected (e.g. Irvine et al., 2009; Malcomson et al., 2008), pwMS may feel they are fundamentally different (e.g. Green & Todd, 2008; Kralik et al., 2003) or that a part of themselves is lost (Olsson et al., 2008). But often MS is gradually negotiated and integrated into self such that the self is not defined by MS (e.g. Reynolds & Prior, 2003). By planning and organising daily life to take account of symptoms, pwMS report being able to better manage important things in life like spending time with family (e.g. Olsson et al., 2008; Payne & McPherson, 2010) and engage in activities that provide a sense of ‘biographical continuity’ (Reynolds & Prior, 2003). In this way pwMS can be accepting of their changed body,

recognising its frailty, desiring to nurture it and work with the MS (Kralik et al., 2003). Positive reactions, support and affirmation received from loved ones enable pwMS to manage symptoms, to integrate an MS self and cope with a changed life (Kralik et al., 2003). Participants in Irvine et al. (2009) noted that when loved ones are supportive and positive, they are a source of hope and coping. Some of Malcomson et al.'s (2008) interview participants whilst acknowledging relatives worried about MS felt they were a "great source of support".

Husbands and wider family play an important role in enabling women with MS to be mothers and to manage parental responsibilities (Payne & McPherson, 2010). Husbands' support to manage tasks they could achieve was crucial to women feeling they were involved and contributing to family life. Some research suggests that there may be some gender-differences in caregiver roles taken on by husbands and wives of pwMS causing slight differences in type of support offered. Courts et al. (2005) found men were "protectors" who helped their wives conserve energy and made sure she did activities that promoted self-worth. Women were "advocates", keeping their husbands involved, obtaining any support needed whilst encouraging their independence (see also Bogosian et al., 2009). Both sorts of behaviour appeared accepting and encouraging but the perceptions of pwMS were not investigated.

In terms of attractiveness and sexual relationships, Esmail et al., (2010) noted that for men with MS sexual functioning changes led them to re-evaluate their relationships, experiencing their partner as accepting was very important. Similarly in Koch et al.'s (2002) investigation of women's constructions of sexuality in the context of MS, changes in relationships affected the way they saw themselves and it was important for them to feel valued by their partners regardless of MS, even when they may feel changed in the eyes of the other i.e. "I'm not the girl he married" (Irvine et al., 2009).

Women have described how good it feels being welcomed in the same way as when they were healthy (Olsson et al., 2011). For pwMS supportive social relationships are regarded as important (e.g. Reynolds & Prior, 2003). Whilst old friendships may continue, new ones may also develop after diagnosis. PwMS have noted how having friends with MS can be helpful (e.g. Irvine et al., 2009; Olsson et al., 2011). MS support groups could be a source of support where “everybody understands and everybody knows” (Irvine et al., p. 4). Some literature suggests that positive experiences of health professionals may be in a minority for pwMS (Malcomson, et al., 2008) but, women interviewed by Olsson et al. (2011) felt recognised by health professionals, reporting instances of feeling listened to and taken seriously. Being accepted and understood in this way was accompanied by a sense of relief and support. Supportive relationships are also important for loved ones. Bogosian et al. (2011) noted that the well parent, family and friends could be a great source of support for adolescents. The availability of a good support network for the adolescents mediated the impact of parental MS: “You can’t underestimate how much family helps” (p. 435). For female partners, having friends with whom they could share worries was helpful (Bogosian et al., 2009).

Discussion

The current review reports the relational impact of MS across relationship spheres using CAT to organise the literature and encompasses familial and wider social relationships. The author is not aware of CAT being used to collate and consider published material in this way before. Results reveal relational aspects of MS. It seems that as MS changes the physical body this influences not only how pwMS view and relate to themselves, it influences how others view and relate to them. Clear relational dynamics emerged from the narratives in the literature that appear to occur again and again in the relationships of pwMS. Such dynamics seem to stem from the progressive nature of MS that causes a shift in the caring-cared for role. The unpredictable nature of

MS means this shift varies: it may be temporary and associated with relapses or enduring when functional losses deteriorate progressively. Every family member feels the impact of MS (Bowen et al., 2011) and the burden of caring can create distance between pwMS and their loved ones (Grytten & Måseide, 2006).

The relational patterns noted in this review appear to make a difference to effective coping and adjustment to MS. For example, the literature highlighted that overemphasis upon MS can be unhelpful as it can leave pwMS feeling infantilised and useless causing them to withdraw from others and become socially isolated. The effect of relational patterns on isolation is important to consider given that strong social support networks are widely acknowledged to be important for the mental wellbeing of pwMS (e.g. Patrick, Morgan & Charlton, 1986). Beal and Stuifbergen (2007, p. 169) noted that “a sense of estrangement from others often accompanies prolonged illness” but this impact on relationships can be ameliorated.

Relationships may need “remodelling” as a result of changes imposed by illness (Lyons & Meade, 1995). A CAT framework clarifies relational patterns and supports consideration of where relational difficulties may benefit from support. Figure 2 provides an initial attempt at a CAT-informed diagrammatic formulation that summarises the key relational themes observed in MS. It suggests how relational patterns may link together and interact with mood. The content is derived from and evidenced in the literature reviewed. For example, when others are over involved or overprotective, this can leave pwMS feeling degraded and a failure (Grytten & Måseide, 2006). Being met in this way can lead to withdrawal from others which can lead into a relational pattern of feeling rejected which further fuels feeling isolated and alone. Feeling alone can have a negative impact on wellbeing and mood may deteriorate. The large arrows on Figure 2 indicate points for targeting interventions so that unhelpful roles or loops may be avoided. For example, family members may benefit from support

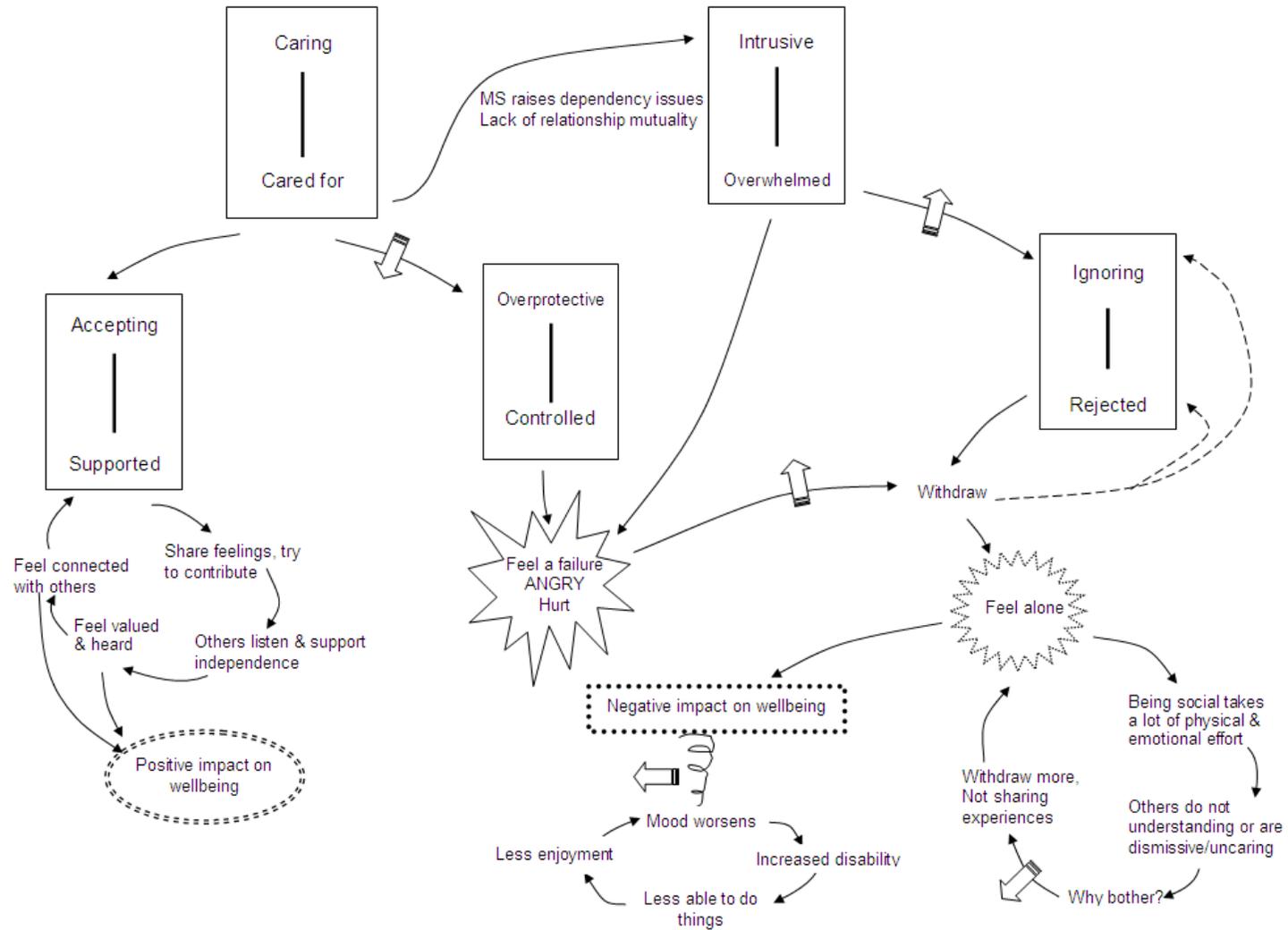


Figure 2. Diagrammatic formulation of relational patterns and mood in MS

to minimise unhelpful overprotection of pwMS. Conversely pwMS may need support to assert their wishes and opinions regarding independence. The literature suggests a delicate balance must be negotiated between independence and dependence as well as between acknowledgement and ignoring of symptoms. In order to minimise feeling a failure or useless, pwMS may need greater support to find ways to adapt activities or find alternative meaningful occupations. PwMS have stated that adapting in this way helps maintain quality of life and self-esteem (Reynolds & Prior, 2003). Services may have a role to play in educating others about MS so that understanding and acknowledgement of difficulties improves in social relationships. This may reduce the prevalence of the “feeling alone” vicious cycle.

Clear communication between partners regarding difficulties and feelings is often cited as important (Esmail et al., 2007; Malcomson et al., 2008) yet sharing feelings is not always easy. PwMS can find it hard to discuss how they are feeling particularly when their partner is their caregiver. McCabe et al. (1996) reported how pwMS coped with feeling “down in the dumps.” Nearly half the sample reported talking to themselves about it, 19% reported they would talk with professionals and only 9.7% would talk with others. Other research (e.g. Sollom & Kneebone, 2007) suggests that pwMS often do not seek help from services for emotional difficulties. Non-help-seeking may compound the problem as depression can seem hard to get out of. Interventions may be needed that support pwMS and family members to communicate feelings. Further research is needed also that explores the experience of depression and emotional distress in MS and the factors that influence support seeking.

Research has revealed that MS affects the emotional wellbeing of pwMS (e.g. Honarmand & Feinstein, 2009) and for a variety of reasons. Depression, for example, may be influenced by neurological changes as well as reactions to coping with MS. This review also highlights that relationships may play a part. Research suggests that

relationships with others have a significant role to play in adjustment to and management of chronic illness (Power, 1985; Fisher & Weihs, 2000). Negative reactions can increase distress in MS whereas supportive ones can assist adjustment to a changed life (Olsson et al., 2008; Kralik et al., 2003). King and Arnett (2005) found that higher depression and fatigue levels predicted worse dyadic adjustment to MS. The exact nature of the interaction between depression and dyadic adjustment is unclear, but the relationship between them is robust which “provides another justification for better recognition and treatment of depression” in MS (p. 796). By understanding the literature using a cognitive analytic stance, further consideration of how relational factors influence mood has been enabled and initial areas for targeted intervention have been suggested.

Although CAT has been a useful and interesting framework, there are some limitations to using it to understand literature. CAT reciprocal roles always have two relational positions of the ‘parent’ and ‘child’, that is, how the other behaves and how the “done to” person feels as a result of that behaviour. The current connections between the two ‘poles’ reported in this review cannot be proven. They appeared to be present but were inferred from the data and therefore may not be causal. Relationships are complex so there may be other pertinent issues or relational difficulties that have not been captured by the published literature and are therefore missing. The relational patterns reported cannot simply be applied automatically to the relationships of every individual with MS and caution must be exercised in this respect. In this review a model of individual therapy was applied to ‘second-hand’ data pertaining to experiences of multiple individuals. The current author did not hear complete personal narratives; she only had access to the information reported in the articles which may have been influenced by researcher biases. Shannon and Swarbrick (2010) developed a CAT framework for the common relational patterns in Bipolar Disorder. Unlike the current

review, the framework was based on extensive clinical experience, process notes and consultation with experts and services users. Further research is needed therefore to find out what the roles highlighted in this review may mean to pwMS. It will also be interesting to consider whether the relational patterns currently highlighted are similar or different to other chronic illnesses.

Murray (1995) noted that MS care which recognises both neurological and psychosocial issues would be most effective. A condition with so many unpredictable and progressive physical difficulties means psychosocial issues can easily become overlooked. Therefore despite the aforementioned limitations, the review provides clinicians with a useful framework to consider the relational dynamics that may be occurring in family's of pwMS and therefore offers a clearer viewpoint from which to consider if specific support or interventions may be necessary.

Conclusion

This review points to the central importance of interpersonal relationships in MS and coping. Due to the unpredictability and uncertainty of the disease course along with the strain caused by the symptoms themselves, it is understandable that relationships can suffer in MS. It seems relationships of pwMS as well as their loved ones are affected. Certain common patterns of relating have been revealed in the literature and it is suggested these can either help or hinder coping and adjustment and affect wellbeing. The relational patterns engaged in by pwMS, loved ones, friends and society in relation to MS are important to understand in order to be able to try and revise unhelpful ones and ameliorate their effects on wellbeing. CAT theory has provided an interesting and useful framework for deepening understanding of how relationships are affected by chronic illness. The development of an initial CAT-informed diagrammatic formulation that represents how relational patterns interlink has allowed further consideration of patient-focused interventions. Services may have a significant role to play in facilitating

understanding and supportive relationships. Although the reciprocal roles highlighted appear to have clinical utility, the opinions of pwMS regarding these roles in their daily lives will be valuable to ascertain.

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Section 2

Empirical Report

“Putting one foot in front of the other” A Qualitative Study of the Emotional Experiences of Women with Multiple Sclerosis.

Abstract

Objective. High prevalence rates of depression and anxiety have been reported in Multiple Sclerosis (MS). Treatments are effective but there is evidence that patients do not always seek help for emotional difficulties. The aim of the current study was to develop understanding of the emotional experiences of people living with MS, what these experiences are and how they are coped with.

Design and methods. Ten women with a diagnosis of MS aged between 30 and 64 participated in semi-structured interviews that were analysed using Interpretative Phenomenological Analysis. At a second meeting the interviewees also gave feedback upon the analytic process and research themes present in their research data.

Results. Three themes emerged from the data: *To be invisible or not*, *Visibility and disability*, and *It's out of my control*. All themes demonstrate the unpredictable and changeable journey of living with and adapting to MS. Of particular note was the fact that often emotional experiences seemed invisible to others yet they were often a source of significant and ongoing stress.

Conclusions. Living with MS involves a range of emotions. Emotions could be overwhelming at times and the women worked hard to manage them on their own. Service and familial support was highly valued but was felt to be limited with regards emotional support. A more holistic service approach would be valued. Help-seeking for emotional difficulties was partly related to perceptions of emotion severity and coping difficulty. A lack of knowledge regarding what services were available was reported.

“Putting one foot in front of the other” A Qualitative Study of the Emotional Experiences of People with Multiple Sclerosis.

Multiple sclerosis (MS) is a chronic autoimmune condition that results in damage to myelin, the protective substance that coats the nerves of the central nervous system (CNS). Partial or complete loss of myelin can occur at any point in the CNS and therefore causes a wide range of symptoms. Common symptoms include visual impairment, bladder dysfunction, fatigue, impaired mobility and pain (Holland & Madonna, 2005). Cognitive dysfunction, i.e. impaired information processing, memory and concentration, can also be a significant problem (Mohr & Cox, 2001). Point prevalence and lifetime prevalence rates of depression and anxiety in people with multiple sclerosis (pwMS) have been found to be significantly higher than in the general population (Beiske et al., 2008; Chwastiak & Ehde, 2007; Dahl, Stordal, Lydersen, & Midgard, 2009; Kessler et al., 2005). The lifetime prevalence of depression for pwMS is rated at between 25 to 50%, and 36% for anxiety (Honarmand & Feinstein, 2009). Sollom and Kneebone (2007) found 50-60% of their 495 participants reported clinically significant depressive symptoms.

Although some research has proposed psychological problems are the result of MS-related brain changes (i.e. lesions), Aitkens, Fischer, Namey and Rudick (1997) noted that most research supported the view that they were a psychological response to the stressful nature of MS. Aitkens et al. noted that MS-related decline in functional abilities may compound the impact of other stressful life events, and that coping strategies influence the severity of psychological distress. More recently, Holden and Isaac (2011) have demonstrated that as well as being an emotional reaction to living with the condition, depression may also be related to the specific neuropathology of MS. Whatever their cause, significant psychological difficulties need intervention.

Mohr and Goodkin (1999, p. 6) stated that pwMS experiencing depression cannot be expected to improve without treatment and “are at significant risk of further deterioration.” The suicide rate in MS is reported to be 7.5 times higher than in age-matched populations (Nocentini, 2006). The emotional impact of MS can also affect treatment adherence and therefore disease course. Results of a recent study (Bruce, Hancock, Arnett, & Lynch, 2010) indicated that emotional difficulties affect adherence to disease-modifying therapies. Individuals with mood and anxiety disorders were five times more likely to display difficulties with treatment adherence (Bruce et al., 2010). Beiske et al. (2008) highlighted that “symptoms of depression and anxiety both independently and in interaction with other MS symptoms affect patient’s functioning” (p. 244). They stated that these symptoms should not be interpreted as a natural and inevitable consequence of the disease course, they must be treated.

A variety of treatments, both pharmacological and psychosocial, have been shown to be efficacious in treating depression in MS (Mohr & Goodkin, 1999). More recent studies have trialled different interventions such as telephone-administered therapies and supportive-expressive group therapy (Mohr et al., 2000; Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001; Mohr et al., 2005). These treatments reduced depressive status in most individuals but the measures used to evaluate treatments vary considerably. Research also suggests that psychological interventions can have a positive impact on disability and fatigue (e.g. Mohr, Hart, & Goldberg, 2003; Mohr, Hart, & Vella, 2007). Despite a relative paucity of evidence, the available research has indicated that interventions can be effective in reducing symptoms of general anxiety (e.g. Grossman et al., 2010; Mohr & Cox, 2001) and in treating injection anxiety (e.g. Mohr, Cox, Epstein, & Boudewyn, 2002) in MS.

Yet, despite the availability of effective treatments for emotional difficulties, it appears that large numbers of pwMS are not seeking or receiving treatment and it is

unclear why. Beiske et al. (2008) stated that only 15.9% of depressed participants and 11.1% of those with anxiety reported any kind of treatment. Sollom and Kneebone (2007) reported that a minority of individuals with clinically significant depressive symptoms reported treatment, around 40% of those scoring >16 on the Centre for Epidemiologic Studies Depression Scale. They predicted that giving feedback regarding depressive symptom level would positively influence help-seeking behaviour, however fewer than 30% of those prompted later reported treatment. Although questionnaires have been validated for use with MS populations they measure symptoms, they do not diagnose depression. Depression may therefore be over-reported due to the overlap between depressive and MS symptoms. Despite this it is important to consider why many individuals do not receive support for significant distress given the extensive research pointing to the deleterious effects of depression on the general health and quality of life of pwMS (e.g. Fruehwald, Loeffler-Stastka, Eher, Saletu, & Baumhackl, 2001) and that there is good evidence for treatment effectiveness.

Various explanations for lack of treatment have been proposed. Sollom and Kneebone (2007) suggested that multiple factors may have played a role: the level of depressive symptoms, practical considerations such as service accessibility, and the perception that depression is “an inevitable consequence for MS for which no relief is available” (p. 634). It is possible that several methodological issues could also account for low treatment-seeking, for example, the nature of being told impersonally by somebody else to seek treatment. Beiske et al. (2008) proposed that limited physician focus on emotional issues may account for small numbers receiving treatments. They also suggested that measures may not match diagnostic criteria for major depression, i.e. individuals are detected who do not require formal help, or scores may not reflect what participants felt to be true about themselves. Patten, Newman, Becker, Riddell and Metz (2007) noted “hesitancy” amongst patients who were invited to engage in problem-

solving therapy, 32 individuals stated they did not want treatment for depression; some indicated this was because they did not consider themselves to be depressed. Beiske et al. noted that only 18.3% of untreated participants expressed a felt need for treatment. How an individual views their illness or symptoms may affect how they respond to it.

Leventhal's Self-Regulation Model of Illness (Leventhal, Meyer, & Nerenz, 1980; Leventhal, Nerenz, & Steele, 1984) also known as the Common-Sense Model (CSM) provides a framework for understanding how individuals cope with illness. According to the CSM the beliefs, or illness representations, patients have about illness influence coping behaviour. Illness representations consist of five attributes: identity, time-line, consequences, cause, and cure/controllability (Diefenbach, & Leventhal, 1996). Individuals categorise and make sense of an illness which determines their behaviour and whether they seek help. Cameron, Leventhal and Leventhal (1993) proposed that care-seeking is driven by representations of symptoms as a serious health threat, combined with perceptions of an inability to cope with that threat.

This model provides several possible explanations for understanding how individuals respond to the emotional impact of MS. If pwMS do not see depression or anxiety as having serious consequences, and/or they feel able to self-manage, they will be unlikely to seek support. Significant distress may be seen as a normal part of the MS illness experience and therefore not threatening. It may also be that other symptoms take precedence if they are perceived as more threatening. Some of Patten et al.'s (2007) patients indicated they did not participate because they did not wish to invest time and energy in depression treatment. Patten et al. proposed that the number of symptoms pwMS experience means they must prioritise which one is addressed at a particular time. Using the framework of the CSM, part of this prioritisation may be related to perceptions of threat. This in mind, there may also be specific barriers to help-seeking related to mental health problems.

Issues of self-denial of difficulty, or fear of stigma regarding receiving support for mental health problems, can play a role in help-seeking behaviour. An explanatory model specific to non-help-seeking for mental distress was developed by Biddle, Donovan and Gunnell (2007). The Cycle of Avoidance (COA) was developed from interview data concerning distress-related beliefs and behaviours in a sample of young adult help-seekers and non-help-seekers. The model takes a dynamic view of help-seeking behaviour, conceptualising it as a circular process in which lay conceptions of mental distress, the social meanings attached to 'help-seeking' and treatment, and the purposeful action of individuals, play important roles. The non-help-seekers seemed to accommodate or deny illness rather than resolve it. There was a distinction between 'normal' distress which was dealt with by 'coping' and 'real' distress which needed treatment and formal help. There was a sense that if one sought help, the distress became 'real' and was associated with stigma. Deciding not to see oneself as experiencing 'depression' may be influenced by desires to avoid stigma and labels associated with mental health care (Corrigan, 2004). Research has noted how perceived stigma (belief that others will view and respond negatively to oneself) and self-stigma (internalised public stigma) for depression reduce the likelihood of help-seeking (Barney, Griffiths, Jorm & Christensen, 2006). Perhaps the COA can provide explanations for non-help-seeking for depressive symptoms in MS?

In chronic illness literature there has been debate about whether questionnaire measures actually capture levels of disease-specific emotional distress rather than clinical depression (e.g. Fisher et al., 2007) and at times distress and depression are used interchangeably. Living with chronic illnesses can be stressful and upsetting, so aside from depression and anxiety, other negative emotional states may be experienced such as grief, anger and hopelessness. In the context of chronic illness it seems important to explore beyond psychiatric diagnoses and cover a broader range of experiences. To date

MS research has focused on the prevalence of depression or anxiety, or on issues related to their treatment; emotional experiences have only been tangentially reported within other qualitative themes (e.g. Irvine, Davidson, Hoy, & Lowe-Strong, 2009). Given issues of stigma, lack of knowledge regarding MS experiences and that sense-making of emotional lives encompasses psychiatric symptoms as well as ‘ordinary’ emotions, a wider term of “emotional distress” is employed in the present study. No research has focused on the daily experience of emotions in MS, yet this is an area with vital importance for quality of life. The aim of the current study was to develop understanding of the lived experience of MS-related emotions as well as to uncover ways in which feelings are managed, coped with and understood. It was hoped data would also point to factors influencing help-seeking for emotional difficulties.

Qualitative research is appropriate when the area of interest is largely unexplored or when personal meanings are the object of interest rather than identification of cause-effect relationships (Willig, 2004). Qualitative methods allow for in-depth examinations of how individuals understand and construct their lives and situations. Researchers attempt to base their understandings of a given phenomenon as much as possible on the perspective of those being studied (Elliot, Fischer & Rennie, 1999, p. 216). *Interpretative Phenomenological Analysis* (IPA, Smith, Jarman & Osborne, 1999) was used to analyse semi-structured interviews. IPA values “insider perspectives” of experiences (Smith, 1996) and is considered a valid approach for health psychology research (Biggerstaff & Thompson, 2008; Shaw, 2001). IPA has a critical realist and constructivist epistemological position, that is, it is concerned with human experience “as it is”. IPA is phenomenological as it focuses on the perceptions of individuals and interpretative as the researcher makes sense of data through the lens of their own conceptions and experience.

Method

Ethical Review

The study was approved by a regional NHS Ethics Committee and a University Scientific Approval process. An MS service user was also consulted during the research development stage to assess appropriateness of the recruitment strategy and to pilot the interview schedule.

Recruitment

The ten female participants were recruited by three Consultant Neurologists from an MS Clinic based within a regional neuroscience centre serving a catchment population of 1.8 million people. An initial introductory letter and ‘consent to be contacted’ form was sent from Consultant Neurologists to MS clinic patients aged 18-65 (Appendix C). Systematic sampling was used to select patients from a database of 260 pwMS living in one city; a letter was sent to every 5th patient. It was hoped this method would avoid bias that might have come from asking members of the Multi-Disciplinary Team (MDT) to suggest individuals. Upon receipt of a ‘consent to be contacted’ form, the individual was contacted by telephone or email to discuss the study further. During the initial contact the researcher screened potential participants. If patients met the eligibility criteria, the researcher sent out the Information Sheet (see Appendix D) and telephoned two weeks later to answer questions and arrange a time for interview.

Participants

Certain inclusion/exclusion criteria were applied to ensure a certain amount of sample homogeneity. All patients invited to participate had received a diagnosis of MS and were aged between 18 and 65. Patients were screened and excluded if they had any other additional serious physical or medical conditions, had a serious mental health difficulty (e.g. borderline personality disorder, psychosis) or were diagnosed with MS

less than 1 year ago. Fourteen pwMS expressed an interest in the study by returning ‘consent to be contacted’ forms but four (one female, 3 male) were excluded due to having a second health condition. The final sample consisted of 10 women. Table 1 below illustrates certain demographic data for the participants.

Table 1

Characteristics of the sample (n=10)

Characteristics	Number
Age (years):	
30-39	4
40-49	2
50-59	3
60-65	1
Type of MS:	
Don't know	1
Relapsing remitting	7
Secondary progressive	1
Secondary progressive with relapse	1
Time since diagnosis (years):	
4-5	2
8-9	3
12-13	3
20-22	2
Level of current disability (GNDS ^a score):	
<10	2
10-19	1
20-29	3
30-39	4
Last symptom flare up:	
1 week	1
1 month	3
6 months	3
12 months	1
Over 12 months	2

^aGuy's Neurological Disability Scale is not a categorical measure. Score groupings illustrate the range of disability within the sample. Higher scores indicate greater disability.

Measures

The use of quantitative measures in this qualitative study enabled the collection of demographic information that helped ‘situate’ the sample (i.e. MS diagnosis, level of disability). The following measures were completed by participants in their own time following the researcher’s departure (see Appendix F for questionnaire samples).

Hospital Anxiety and Depression Scale (HADS). The HADS (Zigmond & Snaith, 1983) was developed specifically for use in medically ill populations and has good validity (Bjelland, Dahl, Haug, & Neckelmann, 2002). It consists of two scales which assess for the possible presence of clinically significant levels of depression and anxiety. A score of 8 or greater is an appropriate cut-off point for detection of anxiety and depression in MS (Honarmand & Feinstein, 2009). Scores range from 0-21 for both anxiety and depression. Higher scores indicate greater distress. Table 2 summarises the HADS scores for the sample.

Table 2

Hospital Anxiety and Depression Scale scores by scale

HADS scale	Score range	Mean scores	No. reaching clinical cut-off
Depression	1-12	6	3
Anxiety	1-16	9	5

Guy's Neurological Disability Scale (GNDS). The GNDS (Sharrack & Hughes, 1999) is a disability measure for MS. The questions cover 12 areas of possible disability including: memory, vision, swallowing and bladder functioning. The postal version used in the current study, demonstrates excellent reliability (Rossier & Wade, 2002). Scores range from 0-60, a score of 60 indicates maximum disability.

General Information Questionnaire. This questionnaire is a set of demographic questions based on the General Information Questionnaire for Multiple Sclerosis (GIMS, Sollom & Kneebone, 2007). It requests various details including MS diagnosis type, time since last flare-up, and whether treatment has been received for emotional problems.

Procedure

Between November 2011 and February 2012 ten semi-structured interviews lasting between 45 and 90 minutes were conducted. Eight interviews were conducted in

participant homes, one at the University and another at a place of work in a private room. Participants signed a consent form prior to the interview (see Appendix E). In recognition of the impact of fatigue for many pwMS, measures were left with participants to complete and return in a FreePost envelope. All participants consented to arranging a second meeting to discuss the study findings. Two participants have provided feedback so far.

In line with IPA guidance (Smith, 1995) a semi-structured interview schedule was developed. It was piloted with an MS service user and revised. The schedule was open to further revision during the interview process to take account of any other issues that might arise or be of interest (See Appendix G). Smith (1995) states that semi-structured interviews allow researchers to gain a more detailed picture of participant beliefs as they allow flexibility to follow up interesting avenues and the possibility of finding issues the researcher has not thought of.

Analysis

IPA takes an idiographic approach to analysis, beginning with specific examples in one interview and slowly working up towards categories that are generalised across all interviews (Smith, 1995). Smith's 4-stage cyclical protocol for data analysis (Smith et al., 1999; Smith, Flowers, & Larkin, 2009) was followed. All interviews were initially read once to give the researcher an overview of the experiences.

Data were analysed on a participant-by-participant basis. The first stage required full immersion in the data through reading and re-reading a transcript. This allowed the researcher to become familiar with the issues raised. Interview analysis began with noting in the right hand margin anything that appeared interesting or significant on a line by line basis. The researcher noted down descriptive, linguistic or conceptual / exploratory comments.

In the second stage, emerging theme titles were noted in the left hand margin. These were key words or phrases that “capture the essential quality” (p. 221, Smith et al., 1999) of what was found in each section of the text e.g. changed self, anger.

The third stage began with transference of the emerging themes onto a separate sheet. Initial connections between themes were observed and clustered using highlighters. The researcher referred back to the transcript to check connections were valid. The list was refined and adjusted, allowing the theme clusters to move from general to specific, from purely descriptive to interpretative in their content. The researcher produced a table detailing each higher (or superordinate) theme with its subthemes, including examples of where the theme could be found in the text of each transcript. Once the emerging themes and clusters had been generated for one participant, the researcher set that interview aside and started the process again with the next transcript.

Following completion of analysis for each individual interview, the researcher began comparing the accounts and looking for connections across the group as a whole. Initially each individual theme table was cut up and slips were clustered together. Again through a process of refinement, themes moved from descriptive to interpretive until a single set of themes that provided a coherent account of the data was developed.

Quality control

In order to enhance validity the study was designed and conducted in accordance with qualitative research guidance (Elliott, Fischer, & Rennie, 1999; Yardley, 2000). Yardley (p. 222) notes the importance of “fit between the research question and the philosophical perspective adopted, and the method of investigation and analysis undertaken.” The epistemological position of the research was considered and the rationale for the use of IPA was clear. The sample was ‘situated’ using demographic details allowing readers to judge whether the findings are relevant to their context.

Analysis involved full immersion in the topic area and data, and attempts were made to ‘bracket off’ pre-conceptions. Competence and skill in the methods were developed through personal study and regular supervision. Detailed records of the process of data collection and analysis were maintained, and evidence is provided of the analytic process (Appendix H provides a worked example). The results are ‘grounded’ in the data using relevant transcript excerpts.

Triangulation of analysis credibility. A three-fold method was used: field experts, peer auditors and respondent validation. First, two experts in the field (one expert in IPA, the other worked professionally with pwMS) were each provided with a transcript and table of themes to consider and comment on. Second, peer analytic ‘auditors’ were used to check the method of data analysis according to an agreed protocol (Appendix I). Using these two methods, analysis of 8 interviews was audited. Peer auditors and experts also provided feedback on the overall table of themes. Third, respondent validation was undertaken. All participants consented to give feedback on the analysis. At the time of writing two participants commented on their individual interview analysis and the overall themes. The content of individual tables of themes was discussed with the corresponding participant in person; comments were taken into account and the analysis reviewed as necessary. Feedback received from these three methods was used to refine and deepen interpretation of the interviews themes. In the case of disputes, these were discussed in relation to the raw data. Examples of how feedback influenced data analysis can be found in Appendix I. Figure 1 illustrates the cyclical nature of the data analysis and audit process. The format of the figure is based upon one presented by Walsh, Hagan and Gamsu (2000, permission granted by the senior author).

Reflexivity. Epistemologically IPA relates to the belief that “our experience of the world is profoundly influenced by our assumptions, intentions and actions”

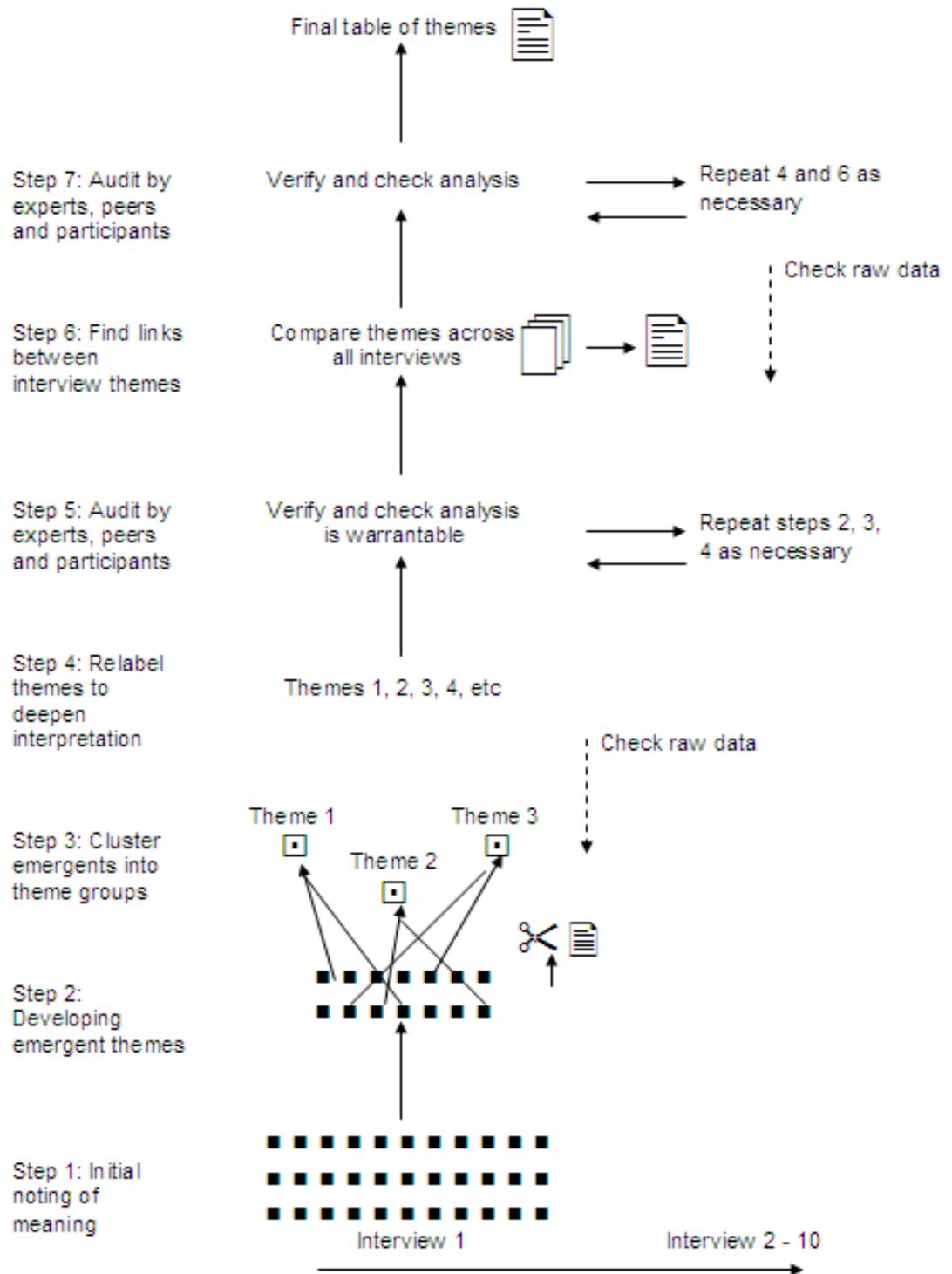


Figure 1. Process of analysis and audit.

(Yardley, 2000, p. 222); therefore an interaction between the researcher, the researched and the data is expected. In order to develop awareness of this interaction and to minimise interpretations being placed onto the data, a reflexive journal was kept. Pre-

conceptions, motivations, personal thoughts and reactions during the phases of study development, data collection and analysis were documented to enable transparency of the process. Issues were discussed with supervisors and within the context of a peer supervision group of IPA researchers. As part of the audit process, auditors were given access to the notes made for the interview they audited.

Results

Three overarching themes along with 12 subthemes emerged from the data (see Table 3). Each theme will be discussed in turn and illustrated by transcript excerpts.¹ In order to support the audit trail, each quote's starting line number is stated in parentheses along with pseudonyms. Two participants provided comments on the themes. Both reported they felt the experiences they shared were captured.

Table 3

Themes and subthemes in the findings

Themes	Subthemes
To be invisible or not	<i>Disclosure dilemma</i> <i>A two-edged sword</i> <i>Invisible emotions</i>
Visibility and disability	<i>Diagnosis as validating</i> <i>Being seen for me</i> <i>Value of physical support</i> <i>Uncomfortable dependence</i> <i>No longer ignorable</i>
It's out of my control	<i>Threat of further losses</i> <i>Threats to overwhelm emotionally</i> <i>Finding control</i> <i>Why I feel this way</i>

¹ Please note: use of *italics* in quotations demonstrates participant emphasis whilst speaking; use of '–' indicates where an excerpt has been collapsed to key statements without loss of meaning; use of '...' illustrates a pause in the participant's response.

To be invisible or not

To be invisible or not is made up of a three subthemes which are illustrated in turn: *disclosure dilemma*, *a two-edged sword*, and *invisible emotions*.

Disclosure dilemma. Whilst symptoms were invisible, pwMS had greater control over whether or not they disclosed their diagnosis. The decision to disclose may not be a one off; as noted by Tina, it was something to be considered with each new person.

“there’s always the whether or not to tell people.” (Tina, 15)

Telling others about their diagnosis was a concern for various reasons. There was a fear of being seen and treated differently once others knew. In particular, of being seen as someone who was disabled or being seen no longer as ‘me’, but only for the disease.

“I felt stupid, I thought people are going to think I’m... I daren’t tell anybody, I didn’t want anybody to know because I thought they’ll think, there’s, I’m disabled. And I just didn’t want that label” (Jenny, 40)

Invisible symptoms or infrequent relapses meant diagnosis could be kept secret from work colleagues. Disclosure was associated with a fear of being seen as incapable. Participants reported a dilemma. On the one hand non-disclosure meant running the risk that allowances would not be made when they were needed. However, people knowing meant opening up the possibility that too much emphasis would be placed on MS. In fact Helen felt work now saw her unfairly as a ‘health and safety risk.’

"especially at work, what I don’t want to do is to, you know, play the, the disabled cripple card, erm, and get treated differently. On the other hand I want them to acknowledge that there are some things that I can’t do, but... I don’t want that to change the way they look at me and treat me" (Christine, 166)

“I don’t want proper, you know, too many special allowances made, I want them to treat me like an-, another member of the team. Erm, because, I work with my *brain*, and not my body” (Christine, 290)

Explaining the cause of symptoms meant risking receiving sympathy or pity which felt unacceptable. Especially as it meant others may become overprotective which could leave the women feeling helpless and useless.

“I don’t think I want people’s sympathy or, it sounds horrible that dun’t it? I do but I don’t, it’s, it’s hard, I don’t know” (Jenny, 297)

“I know it’s people being concerned and stuff but then that just makes it worse, cos then you just feels like you’re some helpless thing that needs to be looked after and I don’t want to feel like [that]” (Tina, 389)

When they did not want to disclose, it still felt tough as the women were left feeling like they were making excuses. Not giving the real reason meant sometimes the women felt others thought they were being rude.

“it was tough in the beginning because my parents didn’t know, my children didn’t know and it was just a case of, oh, you know, if they were sitting on my knee, ‘don’t sit on my left leg if you can help it because – it gave me pins and needles’” (Christine, 131)

Not wanting to admit that MS was having an impact was another reason for non-disclosure and making excuses. Non-disclosure in this way could be seen as a form of denial or defiance, although the women would not admit to others the cause of their difficulty, they knew full well themselves that MS was the reason.

“I don’t want to use it as an excuse, I don’t want to let it win...it winds me up sometimes because that *is* why I’m not going out tonight and that is why I feel like I do” (Jenny, 371)

For some there was a sense of telling people on a ‘need to know’ basis, like Tina who felt disclosure was an indicator of intimacy. Others felt more than happy to share

their diagnosis as it was preferable that people knew rather than be ignored or asked silly questions.

The majority of the sample were mothers and telling one's children about MS was associated with mixed feelings. Women appeared to worry whether their children may find it embarrassing or feel burdened by it. It was a difficult thing for some to face and several therefore tried to avoid it although they saw the benefit.

"I weren't gonna tell her me, but I were advised *to* tell her, coz the younger they are, you know they'll adapt and they will get used to it and stuff" (Jenny, 421)

Even when people know, there could still be a sense of wanting to keep symptoms secret to avoid burdening others or to avoid embarrassment.

"I haven't told anybody I fell over yesterday because I get embarrassed about it" (Karen, 341)

A two-edged sword. This subtheme is an extension of the disclosure dilemma; it is related yet separate as it speaks of the downside of invisibility following disclosure. When the women experienced invisible symptoms (i.e. pain, fatigue, numbness) they could hide their diagnosis and appear "normal." As noted before, whilst this was a benefit if they did not want to disclose, it meant that others found it difficult to fully comprehend their experience of living with MS.

"I had lots of big challenges that weren't as obvious." (Gemma, 333)

"cos people see me and think "well you look alright" but I don't, they don't see me, when I wobble a lot" (Nicola, 333)

Despite disclosure, the invisibility of symptoms meant that understanding or acknowledgment of difficulties was not guaranteed. Sometimes family members even forgot. The women reported that fatigue was particularly hard for others to understand which could cause a strain on relationships.

“[husband] not quite, being able to understand how I can have the time but not energy, not... because a lot of the MS is just invisible, I don't look particularly terrible”

(Gemma, 146)

“it is not just, I'm a bit tired, I think he [husband] dun't realise that I'm *absolutely* I'm gonna collapse in a minute” (Helen, 97)

Invisible emotions. There was a sense of a sea of emotions bubbling just under the surface that women managed to hide or keep under control in order to keep going with their daily lives. Some women felt that the emotional impact was in some ways the biggest challenge they faced partly because it was unexpected.

“I describe myself an emotional yo-yo. I, I f- find my feelings are really quite, labile”

(Brenda, 256)

“for me, it's been the hardest side to deal with, it's like the emotional impact of it”

(Tina, 441)

This depth of emotion was sometimes not seen because it was internal. It was hard for loved ones and others to understand which could cause tension as it was also hard for the women to explain their emotions.

“if you've got, if you broke a leg or summat like that, you can see that; if you've got a cut you can see it. But when it's in here [gestures to head], it's really difficult” (Jenny, 983)

“when my mood gets like that it obviously causes arguments sometimes between you and your partner which it did, you know because of Will's² understanding. It's hard to explain to people” (Helen, 418)

Sometimes the emotional experience of the women appeared to be invisible to services, however experience of support varied. Several had holistic experiences and greatly valued them, whilst others felt that their emotions were not asked about or discussed.

² Pseudonym

“I go for my acupuncture [pain management at hospital] and she always has a chat with me at the same time. She looks at things holistically, err, so she said err, she’s *really*, really good.” (Nicola, 347)

“I haven’t really spoke to anybody, like you’re the first person I’ve spoke to about the emotional things. I’ve never, ever spoke to anyone about that.” (Patricia, 716)

A few had been referred for psychological support and found it very beneficial, but others felt that access was not easy as it was never offered. There were mixed responses to antidepressants. Some valued how medication flattened out the ups and downs, but others felt that once on medication their emotions were forgotten about. Sometimes the suggestion of medication indicated a misunderstanding of their emotion, that it was seen as pathological rather than normal. It seems medication could add to a sense of feelings not being understood or properly seen.

“[Psychology] was very helpful...I sort of think to myself, “once a month?” I almost didn’t want it to, to come to an end” (Brenda, 449)

“And every time I’ve spoke to people about the way I feel be it the GP, or Neurologist, it’s always antidepressants” (Karen, 746)

“I’m on nerve tablets as well you see, so err I think, once they think they’ve got you on nerve tablets that’s, that’s it” (Patricia, 719)

Some women turned straight to family for support whilst others would rather seek support from services or others with MS primarily. Disclosing feelings could feel difficult for a number of reasons. Alongside the fear of not being understood, there was a fear of burdening others. This meant either not sharing at all or sharing less. Sometimes not sharing was connected to a desire to be self-reliant. Some women, who avoided sharing with family, were left feeling unsupported as they did not know where to turn.

“I don’t want to put too much on him” (Patricia, 610)

“she’s (MS Nurse) been, probably the person that’s been the *most* supportive to me I would say. Yeah. I’d rather tell *her* than my husband” (Helen, 640)

“[diagnosed then] sent out there in the world, to just get on with it – I don’t know if the services exist? cos no one’s *said*.” (Tina, 438)

For several women, the invisibility of their experience physically and/or emotionally meant they essentially felt on their own with the MS. They felt separated from others as they were the one experiencing it. It was hard to explain their experience to others, and family did not always understand how best to support them. Some doubted that others with MS could even fully understand due to the individuality of each person’s symptoms.

“felt like a battle that I was fighting *on my own*, even though my husband, knew about and desperately wants to help me, he doesn’t really.” (Christine, 143)

“in a way, you’re lonel-, you’re on your own with it – I know I get help and things like that but, I feel as though, it’s, it’s got to be me that’s got to cope” (Patricia, 417)

“Coz I can try and explain it to me mum or to me husband or to me daughter but they’ll not know what I’m going on about, they won’t have a clue” (Jenny, 363)

Although emotions could feel invisible to services, all the women felt a strong link existed between the emotional and physical aspects of MS. Talking about the link strengthened beliefs that services needed to see and acknowledge it more, and take a far more holistic approach. Christine hoped in the future that services would routinely check her emotional needs as well as her “are you alive [physical] needs” (1041).

“I’d like to think that they [physical and emotion] were more separate, but not, not in MS, they seem to be crossed” (Brenda, 563)

“we should always consider the emotional side, even if you’ve gone for something physical” (Nicola, 466)

Visibility and disability – the physical nature of MS

The following five subthemes relating to visibility and disability will be discussed: *diagnosis as validating, being seen for me, value of physical support, forced dependence, forced to face it.*

Diagnosis as validating. Although most reported that receiving a diagnosis was a shock, many were also “half relieved” as they finally had a name for the symptoms they had been experiencing. Some had felt they must be a hypochondriac, and felt not understood or supported by family who thought they were just being lazy or moaning. There was therefore value in MS being ‘seen’.

“when they told me I had got MS, I thought ...“At last. Right there’s a reason, there’s a reason for it.”” (Jenny, 22)

“I was relieved in a way because I thought I were going mad! Because there was something, you know “what’s the matter here?” you know, I knew there weren’t something right” (Patricia, 34)

Being seen for me. There was a fear that if/as disability increased, that only the physical impact of the MS would be seen by others. Participants described a changed sense of self in the context of others, of no longer being seen as themselves. It appeared this left them feeling potentially lacking in value, and for some trapped in and disliking their body. When others did still see the women and not the disease, this was helpful and was cherished.

“I just wonder if..., I still do really, if people look at me and think less of me” (Jenny, 271)

“It’s just that they see me *different* now, differently to what you were but you’re still there, you’re still the same person.” (Helen, 870)

“*I’m not* just a person with MS, there’s other stuff going on” (Tina, 121)

Diane felt her biggest MS-related fear was of ending up in a wheelchair. This fear of MS progressing to a stage where the disease was more obvious was voiced by participants because of what that visibility might mean socially for their identity.

“And I thought I couldn’t *bear* people to see me like, *that*, [deteriorated physically] when they’ve seen me like, this, and I thought ‘what would they think?’” (Jenny, 291)

Christine, who used a wheelchair outside the home, noted the difficulty of using it in certain social situations. As she felt different and uncomfortable, she avoided some occasions.

“going to parties and going to bonfire night and just, you know, stuff that people do take for granted, I, I *can’t* do or *won’t* do, because I won’t be sitting with my head, at that level when everybody else is two feet above me” (Christine, 385)

Value of physical support. The vast majority of the women felt the NHS offered a very good service that cared for their visible and invisible physical symptoms (e.g. mobility, pain, incontinence). Services helped the women to manage living with MS, as Brenda put it services helped her to “overcome hurdles.” The MS team also helpfully referred on to other services as necessary e.g. Occupational Therapy, Visual Impairment Social Workers.

“Physical symptoms, that is *absolutely* brilliant... MS nursing team, the Neurologists, yeah, fabulous, I can’t fault them” (Tina, 426)

Having access to MS nurses was invaluable; they understood the disease and answered questions. Some like Diane had not realised just how valuable they would be. MS nurses were a “lifeline” and all valued their accessibility.

“any of the nurses that are there, are wonderful, *absolutely*, it’s a *fantastic* thing”
(Helen,)

“I would almost say that, erm, MS NURSE is more helpful than having a GP but, I can’t say that” (Brenda, 575)

“they’re on the other end of the phone – they *always* ring you back” (Christine, 894)

However, experience of services was not all good. It was particularly reported that GPs and practice staff lacked knowledge about MS. Anxious responses from staff suggesting the women see their MS nurse instead, left the women feeling ostracised and unsupported. Karen felt angry that she had to take responsibility for sorting her treatments, for example, she reported facilitating the exchange of information between professionals.

“it’s really, *really* badly understood by GPs” (Christine, 901)

“I were really took back; it was as though it was some sorta, plague, what you were petrified to get involved with” (Jenny, 874)

Uncomfortable dependence. The deterioration in physical capabilities meant that there was a certain amount of dependence necessary, although for some this was temporary, only during a relapse. The women really needed support to cope with the physical impact. Sometimes others were needed to feel safe, for example, Brenda needed someone around when showering in case she fell.

When needed, physical support from family and friends was highly valued and the women felt blessed to have it. Paid carers, either family or social services, were sometimes employed to help manage.

“I’m, well surrounded by family and friends” (Brenda, 208)

“I don’t think I could’ve got through it if I’m honest. If I didn’t *have him* [husband] to help me how he does, I *do* think I’d be a lot worse” (Jenny, 160)

Nevertheless, this dependence could at times be a source of difficulty like when others became overprotective. The women understood why family did not want them to do too much; however, they could be left feeling minimised and useless particularly as they lost their familiar roles. They disliked having to be reliant on others at times and wanted to be independent.

“*Previously* I was, I think, *very* independent, and capable person. Who was quite, erm, able to, to look after *myself*, and my home and my kids and my husband. But, I think now there’s a big question mark over al-, a lot of those areas” (Brenda, 174)

“my husband’s really good, he’ll do, everything I’m need him to do and *more*, and then I just feel like ‘what’s the point me being around?’” (Karen, 90)

“she’s [sister] youngest, I’m oldest. I’m supposed to look after them *but*, you know she looks after me.” (Patricia, 105)

“HUSBAND, can have a tendency to treat me like I’m not as capable as I used to be” (Gemma, 129)

“they’re quite, precautious on my behalf – Sometimes I *still* like to be able to *do* something myself if I can” (Brenda, 82)

Dependence and change in physical abilities affected identity and how the women saw themselves. Several women compared themselves to older adults.

“I’m, I’m here but, am I a good mother? Am I a good wife?” (Karen, 97)

“You feel sort of old, before, you’re old if you know what I mean?” (Helen, 252)

“I felt so stupid because I couldn’t even, help that older person, I were more decrepit than what they were, and it does make you feel a bit worthless” (Jenny, 510)

The discomfort associated with dependence was not just about losing a sense of personal agency, the women also worried about burdening others and what asking for help might mean. Helen noted that she did not want to be seen as mother that was not managing.

“I don’t think I could do it without him. And obviously I don’t want to tell him that because I don’t want to put him under pressure” (Jenny, 176)

“you worry about your family, kids, erm. You don’t want to be a burden” (Helen, 437)

No longer ignorable. One coping method involved trying to ignore or forget MS. Some women stated this approach was now in the past, but for others it was ongoing. Whilst symptoms were invisible, or residual symptoms were minimal, the women could try to ignore MS.

“most of the time it doesn’t impact on me too much physically, so I *can* just kind of pretend it’s not there” (Tina, 367)

“if I’m well, I’m well. I don’t even think about it.” (Diane, 503)

A progression in symptoms or the start of another relapse, served as a sharp reminder that they had MS. Diane noted that she used to try ignoring relapses but they would get worse so she had to accept them. Relapses meant MS interrupted and interfered with life, forcing changes which even if only temporary, were unwelcome and upsetting.

“You can feel really, really well and everything’s great. And then it just comes and just goes “I’m still here.” (Jenny, 429)

“When it has to interfere with me, then, that’s when it’s upsetting” (Diane, 537)

Brenda noted that until her first relapses, she thought she could turn her back on MS. Similarly Helen initially returned to her “normal self” after relapses so MS did not cause “too much bother.” An increased frequency of relapses or gradual deterioration in abilities made the MS more visible in the lives of the women forcing them to see and acknowledge limitations, and face losses.

“it is starting to be a bit more, obvious and a bit more difficult, I get more relapses – the last *big* relapse was in May and that knocked me back, I couldn’t walk” (Helen, 59)

“I had my first relapses, erm, in 2005. And then my life has *really* ch-changed completely. That I can no longer work” (Brenda, 15)

It’s out of my control – the emotional impact of MS

This theme covers the emotional impact of MS which is partly related to the condition’s unpredictability: *threat of further losses, threats to overwhelm emotionally, and finding control.*

Threat of further losses. Losses could be temporary as with some forms of relapsing-remitting MS, although participants spoke of a gradual progression of loss in several areas of their lives as well as facing the prospect of more loss.

“it’s taken quite a lot of things away from me already, it will almost certainly take *more* things away and they’re things I *value*” (Christine, 750)

Most notably the women spoke about the effect of symptoms on work and being able to fulfil their mothering duties. Some women had stopped work completely although they had tried to keep working as long as they could. Adjustments were vital at work, some still worked full-time but others worked reduced hours or were facing imminent changes.

“my career and my retirement are now the same length. Seven years working then seven years not working” (Gemma, 92)

“about two years ago, I started reducing them temporary. And *now* erm, I’m, I’ve reduced them permanent, which is a financial impact, it really is. It’s really *difficult* but I had no choice” (Nicola, 103)

Seven of the women were mothers and all reported MS had impacted on being able to mother as they felt they should or wanted to. This left them feeling sad and guilty.

“I *can’t* always do the things that she [daughter] wants me to do because I’m fatigued really bad” (Nicola, 59)

The unpredictable nature of the disease meant the women did not know what may happen in the future, what a relapse may bring. The possibility of further functional loss was feared. Sometimes managing the uncertainty of what symptom may appear was a daily battle to be faced, like Gemma whose senses could suddenly disappear.

“if this is how I am now what’s it going to be like in the future?” (Helen, 435)

“With MS, nobody knows why, when, how, how long will you have it, will it/how many more relapses will you have, will you have any this year, will you have any this week, will you have any this month, how long will they last? (Jenny, 647)

“my time as a healthy person is, potentially quite limited you know because, it could go just awful, and I could end up really disabled.” (Tina, 202)

Although it felt awkward to admit, some shared it might be easier to have a different illness other than MS, one that was more predictable and treatable.

“I really feel “gosh that’s awful” but in some ways I kind of think ‘well, you know, you have cancer, you die or it’s treated and you’re better. You don’t have to, it’s not like a life long thing” (Tina, 229)

Some women tried to cope with the uncertainty of the future by avoiding MS-related information and MS others. Seeing others with more progressed symptoms only served to remind them of what might happen.

“I’d be looking at everybody else probably worse than me, and then ‘am I gonna be like that one day? How much longer am I gonna be until in a wheelchair like you.’” (Karen, 665)

Threats to overwhelm emotionally. Whilst the appearance of new symptoms could be particularly overwhelming, the women reported a variety of emotions in their current daily experience as well as over the course of their illness. This emotional changeability was described by Brenda as feeling like an emotional yo-yo. Anger, frustration, depression, anxiety, guilt and grief were common. Some also described having lots of MS-related questions including “why me?”

“just feeling a bit, lost at sea, kind of again to those... I think it’s almost like getting a diagnosis again in a way [progression in symptoms], it just churns all those things [feelings] up again” (Tina, 380)

As the women reflected on what they had lost or what they might still lose, there was a strong sense of pain and grief.

“I think you feel a bit of a loss actually, I suppose, that the life that you had before, has gone” (Helen, 215)

“it’s *not* what I’d envisaged and so I feel cheated, of that which makes me cross” (Christine, 497)

There was a sense that a “deep dark hole” of emotion was not far away. Some had been in “dark places” in the past and were fearful of suicidal thoughts. Emotions threatened to overwhelm, and it felt like it would be easy to sink into a depression.

“I don’t have them now [suicidal thoughts], I don’t want to, it’s dangerous if you let yourself get, lonely, sad” (Jenny, 776)

“I do go on little downers, er every so often, erm so, I do think yeah. I could easily, I could easy go in err, longer” (Nicola, 231)

Although things at times could feel bleak, the women also reported a strong desire to overcome and not be beaten by the MS.

“even though I’ve got *quite* a lot of things going on at the moment that could quite easily make me go into this deep dark hole, I’m not letting it” (Helen 743-746)

Finding control. None of the women wanted to “give in” to MS so they looked for ways to manage symptoms and their overwhelming feelings. Some women wanted to defy it and were determined not to let MS “win.”

“I kind of refuse, I spit in its eye, if you like, I *won’t let it* define, I, I won’t let it affect my identity, if I can help it” (Christine, 417)

“I’ve always been determined in my mind that I won’t let it...make me, er, carry great disability in life, mentally I keep strong with it.” (Diane, 684)

Sometimes women coped by deliberately attempting to make MS invisible by not talking or thinking about it. Women sometimes tried to deny the existence of symptoms; Gemma described how she initially “just ploughed on through” until she could not deny MS’ impact any longer.

“I don’t wanna be thinking about it all the time” (Karen, 887)

“I avoid groups and stuff like that because I just, don’t want to focus on it that much” (Christine, 177)

Women fought to find and maintain some sense of control and reported a plethora of coping methods. There was a sense of just “getting on” with it, of not

moaning and wanting to avoid self-pity. Keeping positive and thankful was thought to be incredibly important to manage mood and keep going. Women tried to focus on achievements and what they could do. Some tried to mentally stay in the present moment, taking things one day or even one moment at a time. As part of staying present and positive, capturing negative or self-critical thoughts was crucial. Several women shared how their faith also helped them to cope.

“I’m not going to get rid of it so I’ve just got to get on with it” (Patricia, 549)

“*everything’s* an adventure and *everything’s* a triumph – if you’ve changed a duvet, my goodness that is an Olympic sport” (Gemma, 734)

“Just live in the moment, it’s much easier” (Tina, 252)

“I’m gonna try and just do the best I can, put one foot in front of the other or, mentally if not physically so” (Christine, 1108)

Taking care of the body was deemed important by the majority. The women engaged in exercise such as yoga or swimming, tried not to push themselves too hard, rested, and sought treatment when needed. Some felt it was important to keep active and do things whilst they could.

“I have to look after myself, I don’t want to *make* myself ill” (Tina, 166)

“*while I can*, I’ll do it, because I know there’s times when I can’t do it *at all*” (Helen, 604)

In contrast, Christine had a different response to her body; it was no longer her friend. There was a sense of wanting to hasten death because she knew greater physical deterioration was inevitable. She had actively begun smoking again and also hoped in the future that assisted suicide would be an available choice.

“I actively *don’t want* to live, a, healthy life because I *don’t* wanna live to be very old.” (Christine, 688)

Distraction and keeping busy were useful strategies when women felt hopeless, sad or fearful of the future. Getting focused on something else or taking a mental step

back were ways of avoiding downward spirals into depression and “dangerous” thoughts. It could also be important not to blame everything on the MS

“I’ve got to keep busy, I’ve got to because otherwise, I know how I’ll get [low with suicidal thoughts] and I can’t bear feeling like that” (Jenny, 766)

“be a bit more objective about it – so I stop and say ‘calm down. Breathe.’” (Tina, 304)

A sense of control could be found by working with MS and listening to their body. The women recognised they could not get rid of MS so they needed find ways round it, for example by adapting things slightly or creating a “Plan B or C”, although this required accepting that changing plans was allowed. There was a need to alter self expectations and accept a “new normal.” Managing was important but it required a lot of “balancing” which was hard.

“I *think* whatever you have you just have to *learn* to live, with the side of it” (Nicola, 26)

“I guess in a nutshell, just accepting that life is *very* different but *not worse* is the way to approach it for me” (Gemma, 247)

As noted previously emotions were sometimes shared with others although this was not easy. Those who had not received input before thought psychology or counselling may be valuable, as long as the person knew about MS, listened non-judgmentally and it was convenient. A few women felt their partners may not encourage them to attend therapy as they preferred to keep things private. The women felt this would not hinder them accessing therapy if they felt it would be beneficial. The value of emotional expression was noted, whether having a good cry, moan, or writing about things.

Why I feel this way. The women had several explanations for their feelings. Some very clearly saw a direct link between the neuropathology (lesions) of MS and depression. Even those that saw this link did not see that changes in their neurology were the only cause. All women saw their feelings as a direct response to coping with

and adapting to MS. They believed that changes in physical symptoms and capabilities were strongly related to feelings; they could not do what they wanted to and MS had stolen things from them. Sometimes feelings were related to MS treatments i.e. side-effects, or to facing a relapse.

“my brain’s got lesions all over it. It doesn’t just affect how I move, it affects how I *think*” (Karen, 525)

“you do feel angry about it that it has taken so many things from you, and it is only that, it is only that that stops you” (Helen, 383)

“you get depressed because you can’t do the things that you really *would like* to do” (Karen, 213)

Some felt their personality played a role in how they coped, that they were naturally more anxious or more upbeat. The role of life events outside was also a major part of their emotional experiences; MS was not the only thing going on in their lives. Some could also see the normality of parts of their emotional experience; it was normal to get down or frustrated when you were over tired, stressed, feeling unwell or it was wintertime.

“To be honest, when I were *first* diagnosed, it was the *least* of my worries because of other things what had happened in my life” (Nicola, 6)

“you’ve got a million and one other things, it’s not just dealing with that” (Helen, 491)

Discussion

This study presents an exploration of ten participants’ experiences of living with MS focusing particularly on emotions. Ten women participated in semi-structured interviews, which enabled their stories of coping to be elicited. The centrality of emotions to the women’s daily lives was highlighted and also evident in their narratives of coping over time. Invisibility and visibility of physical and emotional experiences were emphasised as important issues. There was a tension between wanting things to be hidden yet wanting to receive acknowledgement and support. Relationships with others

and the self were affected negatively at times but the women had developed ways to manage living with the emotional and physical challenges MS presented. The unpredictability and uncertainty of MS was particularly difficult to cope with but the women strove to focus on the positive and the present moment and not worry about the future. Emotions were sometimes the most difficult thing to deal with but many felt insufficiently supported by family and/or services. The current research will be considered in terms of its contribution to current knowledge and theory as well as its limitations and implications.

The themes presented in this study are consistent with narratives raised in earlier research, for example, feeling perceived as different due to a changed body (Olsson, Lexell, & Söderberg, 2008; Olsson, Skär, & Söderberg, 2011) or getting to a point where MS is no longer ignorable (Mozo-Dutton, Simpson, & Boot, 2012). Research has reported a plethora of strategies used by women to cope with MS-induced changes (Malcomson, Lowe-Strong, & Dunwoody, 2008; Reynolds & Prior, 2003). Miller (1997) briefly noted participant difficulties with revealing their diagnosis. The unique contribution of this study is that it has focused specifically on emotional experiences in MS and views other issues through an emotional 'lens'. It has noticed a range of dilemmas related to visibility that must be negotiated by pwMS as part of the emotional journey. Loved ones and services may underpin the success or otherwise of these negotiations.

The participants noted how the physical and emotional aspects of MS were intertwined yet they felt to some extent their emotions were invisible, particularly to services which was hard. Despite this invisibility, an awareness of the link spurred some participants on to manage their emotions and MS symptoms to avoid deterioration in either. Research has shown a consistent association between stress and exacerbation of symptoms (Mohr, Hart, Julian, Cox, & Pelletier, 2004). Diane and several other

participants were very aware of this association. Managing stress and taking care of oneself were deemed important to minimise relapse occurrence if possible. Relapses were difficult, emotionally and physically. Papers have discussed the specific emotional impact of relapses (Halper, 2007; Kalb, 2007). Diane stated she felt fine until a flare-up started, so the absence or presence of emotionality can be seen as contingent on relapses. Tina described how a change in symptoms churned everything up (380) that it was like getting a diagnosis again. As relapses occurred or symptoms progressed, the women appeared to describe how MS forced feelings such as anger and grief to be faced. Symptom changes appeared to require a fresh adjustment or grieving process. Charmaz (1995) proposed that adjustment to chronic illness is not a one-off event but a process that needs revisiting with each subsequent change or loss.

Loss and change were central to the emotional experiences of the women. The ways in which they coped with losses and changes is compatible with Stroebe and Schut's (1999) Dual Process Model of Bereavement (DPM). They proposed that when faced with loss people oscillate between *loss orientation* and *restoration orientation*. In loss orientation the individual focuses on aspects of the loss experience. It encompasses grief work and is initially characterised by feelings of sadness and depression. Restoration orientation is focused on coping with secondary sources of stress i.e. changes created by the loss. It is characterised by "getting on with it", of adjusting to changes, to new roles and responsibilities. It also includes distraction from or denial and avoidance of grief. The narratives shared by the women in this study appear to demonstrate an oscillation between these two orientations. As they lived with MS the women experienced periods of grief and sadness over losses but overall it seemed they wanted to try and just get on with life. Stroebe and Schut noted that oscillation between confrontation and avoidance of grief is necessary for optimal adjustment to bereavement. The women had times when they desired to cut-off from their losses and

forget. Taking 'time off' from grieving is seen as helpful but too much avoidance can be detrimental.

The DPM was developed to describe ways of coming to terms with the loss of a close person. Although the authors noted the model's potential applicability to other loss experiences, it has not been systematically explored. It has never been applied to coping with the progressive losses of a chronic illness like MS. The women described a process of trying to move on with life then MS would remind them it was there by changing, causing further losses. The recovery process implied by the model (that the loss focus gradually decreases) may therefore not apply so readily. If pwMS see their emotional experience as primarily a grief process, where strong feelings come and go as part of coming to terms with MS, this may explain a lack of help-seeking. Although the opinions of pwMS regarding this model's interpretation of their coping are as yet unknown, grief was not the only feeling reported by the women in the current study. The women clearly stated experiencing depressed feelings, although they tended to minimise them.

Whilst the women seemed to downplay depressive symptoms or distressed feelings in order to be able to keep coping, the presence of such feelings was experienced as threatening. But, psychological help would only be sought if a certain level of distress was reached. For example, Tina stated she would seek help if everyday she felt she could not cope with it all (541). The women had a multitude of strategies to keep emotions at bay and there was a sense of prioritising physical symptoms which were more demanding and immediate. If the women did feel persistently overwhelmed emotionally, it seemed support would be needed as emotional difficulties on top of the physical ones would be too much to handle alone. In relation to the CSM, it appeared that the women did not seek help as they were able to represent their distress as minimally threatening most of the time. Their narratives suggested distress could be seen as

minimally threatening because the intensity of distress was changeable (not constantly there) and was not totally related to or caused by MS. Since other life events were seen to play a role maybe distress was normalised. Interpreting their emotional experience as normal could be one explanation for pwMS not seeing themselves as depressed when they score on a measure. If an individual does not think they are depressed, they will not seek treatment.

Understandably depression and anxiety have received much attention in MS research given the reported high prevalence and detrimental impact on health. In contrast to this focus, this study demonstrated a tendency for pwMS to downplay or normalise depressed feelings and other emotions. Biddle et al.'s (2007) COA model understands this as a way of accommodating or denying illness. The model proposes that by interpreting distress as normal, people are able to avoid seeking help which is associated with stigma. 'Real' distress is different to normal distress and does require external help. Feeling down, frustrated or angry with MS may be interpreted as normal distress, a normal reaction to loss and change. 'Real' distress may be interpreted by pwMS as only 'severe' depression or severe difficulty coping. In the current study it seemed the women tried to maintain their feelings in the 'normal' realm by keeping them under control, however, feelings could reach a point where support was needed.

Several of the women in the current study had previously sought help for emotional distress. Four of the eight participants who reported low mood in the past had seen a mental health professional for issues related to living with MS at that time. Six participants reported current prescriptions of anti-depressants. The sample therefore consisted of help-seekers and non-help-seekers. All the women appeared to describe a process whereby distress would have to reach a certain level before they considered getting help. Unlike Biddle et al.'s (2007) sample, there did not seem to be the same sense of continually shifting the threshold before help was sought. This may be related

to having an unpredictable physical condition to manage alongside any distress, as well as a need to keep going and managing because of other responsibilities like childcare. If things got bad, the women could not afford to let them deteriorate further because of the link between the physical and emotional.

The current findings suggest the COA model of help-seeking for mental distress may be applicable to adults with chronic illness although it does not completely capture the experience. The model sees help-seeking as a dynamic process influenced by social meanings and focuses on the role of stigma. Stigma related to receiving mental health support was barely mentioned by the women as a barrier to help-seeking. Even if partner attitudes were expected to be reluctant regarding therapy, the women said they would assert they needed the help. Two other social issues not currently covered by the COA model were raised in this research: a desire to avoid burdening or ‘bothering’ others and/or services, and a sense that other people are more deserving and needy. These may be important influences on non-help-seeking behaviour. Even though these issues are unlikely to apply to all individuals experiencing mental distress, further investigation would be beneficial. Given the tendency of participants to try and cope by themselves and their reported desire to defy MS, it is proposed that the motivating factor for wanting to normalise distress in MS may be an avoidance of MS “winning” rather than avoidance of stigma as in the original model.

Limitations and suggestions for future research

Three men expressed an interest in the project but met exclusion criteria resulting in the study’s sample being entirely female. It is unknown whether male experiences of emotions and coping will be similar so this should be an area for future research. Although a range of MS types were represented by the participants, each person’s MS experience is individual therefore the findings may not reflect the experience of emotional distress for other women outside of this sample.

Epistemologically IPA posits there is no “one truth”, all perspectives are useful and add to meaning making of phenomenon. Nevertheless, inherent in IPA methodology is the possibility that the interpretative endeavour is unduly influenced by a researcher’s experiences, knowledge and motivations. The current researcher’s professional training meant she had a strong belief in the value of understanding and expressing emotions especially through psychological interventions. This primary motivator for researching the topic could have biased data collection and interpretation. However, the researcher was aware of owning her particular perspective and took steps to minimise bias (for example by checking interpretations were grounded in the data and using respondent validation).

One well considered limitation of collecting data via qualitative interviews is that interviewer characteristics, such as job role or perceived differences (i.e. class), can influence interviewee responses (e.g. Britten, 1995). The current participants were aware of the researcher’s profession as well as her medical condition (which had to be disclosed for health and safety reasons). It may have been easier for participants to identify with and feel heard by someone with a health condition. Participants may have found it easier or harder to be open knowing they were speaking to a psychologist. Nevertheless, response bias was deemed minimal as participants appeared to speak in an honest and thoughtful way without censoring their narratives (evidenced by sharing embarrassing stories or swearing).

Clinical Implications

The participants clearly voiced how they felt about the support they received and what they did or would value. Although some expressed reticence about formal talking therapies, all valued having individuals with whom they could share concerns and feelings. Services appeared to not always do a good job at facilitating pwMS to share concerns which was problematic when the women did not feel able to confide in friends

or family. A few women noted the value of the interview experience, stating that their reason for participating in the research was because they felt that emotions were neglected by services. Services should therefore consider making their approach to MS management more holistic and aim to ensure all practitioners work holistically. Clinicians should be equipped to consistently raise emotions as an acceptable topic for discussion in consultations.

A few barriers to accessing psychological support were noted by the women. Knowledge of what was available and who to contact were crucial. PwMS may value periodic reminders of the services that are available, Helen noted there was a lot to take in at diagnosis and information given gets forgotten. The women thought appointment times and locations might make access harder, but these barriers were not paramount in their minds. The main issue potentially affecting help-seeking in this sample was in essence believing and accepting oneself that help was needed. When emotions were visible to others, some women noted that if family or known professionals deemed psychological support would be beneficial they would try it even if they themselves were not sure it was necessary.

Conclusions

Ten women shared their emotional experiences of living with MS from diagnosis to the point of interview. Emotions were central to their experiences and they reported a depth of emotion in their daily lives. Many emotions related to the value or drawbacks of aspects of their experience being seen or unseen, along with a focus on MS imposed losses and changes.

The narratives of emotional distress appeared to illustrate a cyclical process where each relapse or progression in symptoms could potentially cause a fresh wave of strong emotional reactions such as grief. These had to be managed in order to keep going with life and “not let MS win.” A variety of strategies were used to cope with the

physical and emotional impact of MS and the women appeared to oscillate between loss-focused and reorientation-focused coping activities. Their emotional experience could feel invisible to others and sometimes neglected by services, yet it had been and remained a key part of living with MS. The women mostly tried to cope with emotions by themselves, but all felt they would be open to receiving psychological support should they need it in the future. Nevertheless difficulty coping would have to reach a certain point before support was sought. Some were unsure whether their experiences would be understood which made them a little hesitant to share. For the women in this study one barrier to accessing support was lacking knowledge of what was available.

This study provides an initial exploration into the detail of the emotional experiences of women with MS and their coping. It provides some further understanding of what may influence help-seeking in MS, in particular, how emotions are interpreted. Further research investigating the emotional experience of men with MS is needed as well as further consideration of the utility of the DPM and COA models in understanding how pwMS cope with emotions. Further investigation of these issues may lead to service interventions that successfully promote accessing psychological support when needed.

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Section 3
Appendices

Appendices

Part 1 Literature Review

Appendix A - Quality Assessment Criteria

Appendix B - Detail of studies included in the review

Part 2 Empirical Report

Appendix C – Ethics Approval Letter

Appendix D – Participant Invitation Letter

Appendix E – Participant Information Sheet

Appendix F – Participant Consent Form

Appendix G – Measures

G1 – HADS

G2 – GNDS

G3 – GIQ

Appendix H – Interview Schedule

Appendix I – Example of Analysis

I1 – Annotated Transcript

I2 – Emergent Themes

I3 – Excerpt from Individual Theme Table

Appendix J – Quality Control

J1 – Peer Audit Protocol

J2 – Summary of Feedback

Appendix A

Quality Assessment Criteria

Quantitative studies

Item Definition	
<i>Rationale- aims</i>	A: positive if the objective of the study was sufficiently described
<i>Demographic variables</i>	B: positive if information was reported on pwMS gender, age, disease type/course, disease severity, time since diagnosis, current MS status (at least 3 of these) AND if a relative-focused study: their gender, age, nature of their relationship with pwMS as well as the previous
<i>Suitability of the design to answering the research question</i>	<p>C: positive if appropriate research design was used, e.g. positive if control group was used when comparing psychopathology to the healthy population, if cross sectional design was used to find associations among the variables (not suggest causality or predictors), or qualitative methods were used to investigate in depth pwMS's or relatives experiences</p> <p>D: positive if control group was equivalent in age, sex and socioeconomic status with the single difference that the person did not have MS (comparative studies only)</p> <p>E: positive when analysing separately different age groups when people in a wide age span were studied or include a single/specific age group</p>
<i>Statistical analysis</i>	F: positive if appropriate statistical methods of analysis were used for the data
<i>Presentation of the analysis</i>	<p>G: positive if the graphs and tables were easy to understand, e.g. presenting a table for regression analyses including R^2 values and β weights</p> <p>H: the confidence intervals or p values were given for the main results</p>
<i>Measures Used</i>	I: positive if all the questionnaires used were standardized, defined as questionnaires that had been validated and published or psychometric data of new measures were presented
<i>Conclusions</i>	J: positive if the conclusions were justified based on the research findings
<i>Limitations</i>	K: positive if key limitations were mentioned

Score classifications: 9-11 = good
6-8 = medium
<6 = poor

Qualitative studies

Item Definition	
<i>A. Report explicit scientific context and purpose</i>	Positive if the manuscript specified where the study fitted within relevant literature and stated the intended purposes or questions of the study
<i>B. Situating the sample.</i>	Positive if authors described the research participants and their life circumstances to aid the reader in judging the range of people and situations to which the findings might be relevant
<i>C. Appropriate methods</i>	Positive if the methods and procedures used were appropriate or responsive to the intended purposes or questions of the study
<i>D. Specification of methods</i>	Positive if authors reported all procedures for gathering data, including specific questions posed to participants. Ways of organizing the data and methods of analysis were also specified
<i>E. Clarity of presentation.</i>	Positive if the manuscript was well-organized and clearly written, with technical terms defined
<i>F. Grounding in examples.</i>	Positive if authors provided examples of the data to illustrate both the analytic procedures used in the study and the understanding developed in the light of them
<i>G. Providing credibility checks</i>	Positive if credibility checks were provided where relevant, these may included (a) checking these understandings with the original informants or others similar to them; (b) using multiple qualitative analysts, (c) comparing two or more varied qualitative perspectives, or (d) where appropriate, 'triangulation' with external factors (e.g. outcome or recovery) or quantitative data
<i>H. Coherence.</i>	Positive if the understanding was represented in a way that achieved coherence and integration while preserving nuances in the data
<i>I. Appropriate discussion</i>	Positive if the research data and the understandings derived from them are discussed in terms of their contribution to theory, content, method, and/or practical domains, with limitations acknowledged

Score classifications: 7-9 = good
 4-6 = medium
 <4 = poor

Appendix B

Detail of studies included in the review

Table B1

Detail of qualitative studies

Author (year)	Aim	Method and sample size	Analysis	Key findings	Quality rating
Boeije et al. (2003)	Explore commitment and caregiving in couples in total care phase	Semi-structured interview 17 couples	Constant Comparative Analysis	Living with MS was a gradual change and learning process for both partners. Inevitability of caregiving. A shared disadvantage. Commitment to prevent admission.	7
Bogosian et al. (2009)	Explore partner experiences of living with early stages of MS	Semi-structured interview (phone) 15 spouses	Inductive Thematic Analysis	Themes: Initial reactions, Loss of control, Constant worry, Lifestyle changes, Social isolation, Attempts to adjust	8
Bogosian et al. (2011)	Explore how adolescents adjust to parental MS	Semi-structured interview 15 children	Inductive Thematic Analysis	Two broad themes: Barriers and enhancements to adjustment, Impact on everyday life	7
Bowen et al. (2011)	Explore experiences of family members following admission of relative with advanced MS	Semi-structured interview 25 relatives	Grounded Theory	Four themes: Information, communication and understanding Family relationships, roles and responsibilities, Emotion, coping and support, Life outlook and reflection.	8
Cheung and Hocking (2004b)	Explore spousal carers' experiences of caring for chronically ill partners	Unstructured interview 10 spouse	Hermeneutic analysis	One of two major themes: Caring as worrying with two subthemes: Worrying about their partner and their relationship, Worrying about the future.	7

Author (year)	Aim	Method and sample size	Analysis	Key findings	Quality rating
Courts et al. (2005)	Investigate lived experience of spouses of pwMS	Focus group 12 spouses	Not stated but hints at Thematic Analysis	Four themes: Caregiver roles, Need for resources, Relational changes, Barriers.	7
DesRosier (1992)	Describe experience and coping of wives with housebound husbands	2 focus groups 9 wives	Constant Comparative Method	Women experienced significant personal hardship. Two themes: Coping, The need for Space.	6
Dyck (1995)	Explore workplace experiences of women with MS	Semi-structured interview 23 women	Not stated	Three sections: Changing lifeworlds, changing space, Restructuring of home and neighbourhood (relocation, modification), The changing experience of place (issues of access and meaning).	5
Edmonds et al. (2007a)	Explore experiences of people severely affected by MS	Semi-structured interview Data relates to 32 pwMS from 23 pwMS and 17 carers	Constant Comparative Method	PwMS continue to experience loss and change in: Physical abilities, Independence, Relationships.	8
Edmonds et al. (2007b)	Explore experiences of people severely affected by MS	Semi-structured interview Data relates to 32 pwMS	Constant Comparative Method	Three themes related to service provision: Fighting for everything, Continuity and co-ordination of care, Information.	8
Esmail et al. (2007)	Understand impact of female MS on couples' sexual relationships	Semi-structured interview 6 couples	Interpretative Thematic Analysis	Women with MS six themes: Communication, Patterns of denial and acceptance, Impact on sex, Partner's needs, Role changes, Love and support. Male partners five themes: Communication, Impact on sex, Role change, Intimacy and closeness, Partner's emotional response to MS.	6

Author (year)	Aim	Method and sample size	Analysis	Key findings	Quality rating
Esmail et al. (2010)	Understand impact of male MS on couples' sexual relationships	Semi-structured interview 4 couples	Interpretative Thematic Analysis	Group themes: Communication is important, MS affected sexual relationship, Role changes, Acceptance of MS supports the relationship.	6
Grytten and Maseide (2006)	Explore stigma experienced by pwMS in social relationships	Semi-structured interview 8 pwMS 6 relatives	Grounded Theory	Two processes were identified: ignoring and overemphasising illness. These impacted social networks and coping.	6
Irvine et al. (2009)	Explore living with and adjusting to MS	Focus group 8 pwMS	IPA	Six key themes: Reaction to/impact of being diagnosed, Social activity, Role in society and self worth, Relationships and dependency, Attitudes/reactions of others, Perceptions of adjustment and changes in self-concept, identity and outlook.	7
Koch et al. (2002)	Explore how women experience and construct sexuality	5 focus group sessions 12 pwMS 9 semi-structured interviews	Participatory Action Approach. Previous constructions of sexuality provided analysis framework.	Individual constructions of sexuality presented and three overall aspects identified as important: Appearance (looking and feeling good themselves), Acknowledgement (feeling valued and acknowledged by others), Communication (with partners regarding sexual changes).	7
Kralik et al. (2003)	Further exploration of transition in chronic illness and the relationship between self and body	5 focus group sessions 12 pwMS 9 semi-structured interview	Crisis Negotiation Model	Exemplars Julie and Lisa illustrate how women's lives are shaped by illness-related identity shifts. A changed body affects sense of self, roles and relationships.	8
Malcomson et al. (2008)	Explore experiences of people who feel able to cope with MS	2 focus groups 13 pwMS	Thematic Analysis	Seven themes: Something is wrong, Getting a name, Getting help, Consequences in lifestyle, Getting on with day-to-day life, Advice to others with MS, Advice to professionals	7

Author (year)	Aim	Method and sample size	Analysis	Key findings	Quality rating
Mutch (2010)	Understand experiences of partners caring for disabled spouse, and explore coping strategies	Semi-structured interview 8 partners	Not stated	Categories for partner's experience: Worry, Planning, Frustration. Categories for strategies: Commitment to marriage, Coping.	8
Olsson et al. (2005)	Explore what fatigue means to women with MS	Semi-structured interview 10 pwMS	Phenomenological hermeneutic interpretation	Two main themes: Experiencing the body as a barrier, Experiencing a different absence. Subthemes cover issues such as being unable to participate and saving strength.	6
Olsson et al. (2008)	Describe meaning of women's experiences of living with MS	Semi-structured interview 10 pwMS	Phenomenological hermeneutic interpretation	Two main themes: An unrecognizable body, Trying to maintain power. Subthemes cover issues such as dependence, feeling seen differently, feeling ignored and wanting to fight as long as possible.	8
Olsson et al. (2011)	Explore meanings of being received and met by others by women with MS	Semi-structured interview 15 pwMS	Phenomenological hermeneutic interpretation	Two main themes: Experiencing oneself as a valuable person, Experiencing oneself as diminished. Women sometimes felt needed and appreciated. They also felt they were seen differently, pitied, misunderstood and a burden.	8
Payne and McPherson (2010)	Explore the experience of motherhood in MS	Semi-structured interview 9 pwMS	Interpretative Descriptive	Six key themes: Public private experience, Keeping baby safe, Enlisting support, Conserving energy, Being the ideal mother, Backgrounding MS.	7

Author (year)	Aim	Method and sample size	Analysis	Key findings	Quality rating
Power (1985)	Identify key family variables influencing adjustment of pwMS	Semi-structured interview 49 families 80% of families seen twice	Not stated. Families classified as positively adjusted or maladjusted.	Many factors contributed to positive adjustment in 23 families including sharing responsibilities and early intervention. 26 families were 'maladjusted'. MS was seen as "an everpresent source of trouble." Communication and understanding were lacking.	4
Reynolds and Prior (2003)	Explore women's strategies for negotiating quality of life in MS	Semi-structured interview 27 pwMS	IPA	Six enabling strategies: Managing illness and limiting its impact, Maintaining and extending meaningful roles, Maintaining mutual relationships, Clarifying personal beliefs and aspirations, Dealing with social barriers, Consciously valuing and promoting the positive.	8
Turpin et al. (2008)	Explore experience and coping strategies of children with an MS parent	Semi-structured interview 8 children	Inductive Thematic Analysis	Three major themes: Changing roles and responsibilities, Emotional Impact, Things that helped.	7

Table B2.

Detail of quantitative studies

Author (year)	Aim	Design and sample size	Analysis	Key findings	Quality rating
Green and Todd (2008)	Examine social and economic impact of MS	Cross-sectional survey 920 pwMS	Frequency of impact in 8 domains Pearson chi-square. Thematic Analysis open-ended question answers	Three-quarters felt impact in at least one domain. 49.3% impact kids; 55.2% intimate relationships: 80% social life/employment. Impact increases as disability progresses. Two themes: restricting choices, limiting independence.	9
Hakim et al. (2000)	Assess social impact of MS and patients' abilities to fulfil roles	Population-based survey 305 pwMS 223 relatives	Few statistical details given, percentages reported. Mann-Whitney U	Disease severity was associated with employment status and levels of social activity. 37% reported decline in living standards. Carers' careers were affected.	6
McCabe et al. (1996)	Assess perceived impact of MS on sexual functioning, social and intimate relationships	Cross-sectional survey 111 pwMS	Descriptive statistics ANOVAs Pearson's r.	Two thirds indicated that sexual interactions were less frequent. Illness duration and level of disability were not predictive of relationship quality, although some participants did report relational changes.	8
Ozdemir and Asiret (2011)	Identification of economic, family, social, and employment issues of pwMS in Turkey	Cross-sectional survey 101 pwMS	Descriptive statistics Chi-square test and independent samples t-test.	71.3% of the sample reported decreased social activity. 49.5% experienced household problems (e.g. communication issues, overprotective family). More MS symptoms were associated with greater home, employment and social difficulties.	7

Appendix C

Ethics Approval Letter


National Research Ethics Service
NRES Committee Yorkshire & the Humber - Bradford

Yorkshire & Humber REC Office

Millside

Mill Pond Lane

Meanwood

Leeds

LS6 4RA

Telephone: 0113 305 0128

03 August 2011

Dr Claire Isaac
 Clinical Neuropsychologist
 Clinical Neuropsychology Services
 Royal Hallamshire Hospital
 Glossop Road
 Sheffield
 S10 2JF

Dear Dr Isaac

Study title: **Understanding emotional distress in Multiple Sclerosis:
 a qualitative study.**

REC reference: **11/YH/0263**

Thank you for your letter of 28 July 2011 responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites
NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	Version	Date
Covering Letter		27 June 2011
Covering Letter		28 July 2011
Interview Schedules/Topic Guides	2	28 February 2011
Investigator CV		
Letter of invitation to participant	2	28 February 2011
Other: Transcriber guidance form		01 October 2010
Other: Student CV		01 June 2011
Other: Susan Walsh CV		
Participant Consent Form	2	28 February 2011
Participant Information Sheet	3	28 July 2011
Protocol	2	28 February 2011
Questionnaire: General information	2	28 February 2011
Questionnaire: Guy's Neurological and Disability Scale		
Questionnaire: Hospital Anxiety and Depression Scale		
REC application		29 June 2011
Referees or other scientific critique report		31 March 2011
Response to Request for Further Information		

Statement of compliance

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

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed

guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

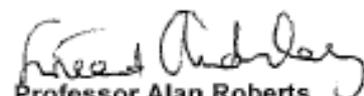
Further information is available at National Research Ethics Service website > After Review

11/YH/0263

Please quote this number on all correspondence

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

Yours sincerely



Professor Alan Roberts
Chair

Email: sinead.audsley@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Ramila Patel, STH NHS Foundation Trust*

Appendix D

Participant Invitation Letter

Hospital Header

Date:

Re: 'Understanding emotional distress in Multiple Sclerosis: a qualitative study' research project

Dear [name]

This is a letter inviting you to participate in a research project that is being supported by the MS Clinic. The research is being conducted by Joanna Blundell Jones, Trainee Clinical Psychologist at the University of Sheffield.

The research aims to explore people's experiences of emotional distress in MS. More specifically it is interested in gaining an understanding of how people cope with this distress and what factors might influence decisions about seeking help. The hope is that this information could help inform services about how they can best support people with MS experiencing emotional distress.

The researcher is hoping to speak to 10-12 people about their experiences. If you would like more information about the study, please complete the enclosed form entitled "Consent to be contacted" and return it to Joanna in the freepost envelope provided. Joanna will then contact you by telephone to talk more about participating in the study. If you would prefer to communicate by email in the first instance, please indicate this on the form.

If you have any further queries please *leave a message* for the researcher, Joanna Blundell Jones, at the University on (0114) 222 6650 and she will return your call as soon as possible. Alternatively send an email to pcp09jkb@sheffield.ac.uk.

Yours sincerely

Consultant Neurologist

Consent to be contacted regarding the research:

Understanding emotional distress in Multiple Sclerosis: a qualitative study.

If you wish to know more about the study, please complete the following details:

Name:

Age:

Home Address:

Telephone Number:

Mobile Number:

If you'd prefer to discuss the study via email please enter your address below.
Email address:

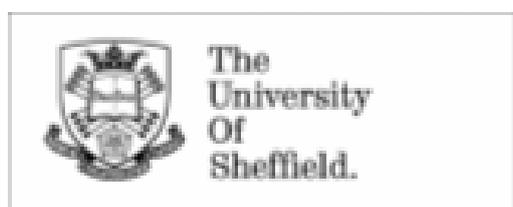
I agree to be contacted by the researcher, Joanna Blundell Jones, to discuss the study and my potential involvement further.

Signature:

Date:

Appendix E

Participant Information Sheet



Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Department of Psychology.

Clinical Psychology Unit

Doctor Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research
training & consultancy.

Participant Information Sheet

Understanding emotional distress in Multiple Sclerosis: a qualitative study.

Invitation

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish. *Ask the researcher if anything is unclear or if you would like more information.*

What is the purpose of the project?

To explore the experience of emotional distress in MS, to learn how people with MS cope with distress and what things might influence seeking help for this distress.

Why am I being invited?

We are inviting individuals aged between 18 and 65 with a diagnosis of MS to consider participating in the study. We are hoping to recruit 10-12 people who are willing to be interviewed about their experiences of emotional distress.

Do I have to take part?

No, it is your choice. If you decide to take part you will be asked to sign a consent form. You can withdraw from the study at any time without giving a reason and any data you have given us can be destroyed. This would not affect your health care in any way.

What will happen to me if I agree to take part?

If you agree to take part you will be interviewed about your experience of distress and MS. The interview will last approximately 60 – 90 minutes which can be split into shorter slots if needed. You will also be asked to complete 3 questionnaires about your mood, your condition and some details about you. You can fill these in after the interview or take them away and return them via a free post envelope. You will also be asked whether you would like to comment on the findings when the interviews have been analysed. This will be entirely your choice.

Will I be recorded, and how will the recording be used?

Yes, the conversation will be tape-recorded. It will be transcribed by a professional transcriber who will adhere to guidelines regarding confidentiality (you can request to see a copy of these). All tapes will be kept in a locked cabinet and destroyed following data analysis. Transcripts of conversations will be anonymised (names and other identifying information will be removed).

Will my taking part in this project be kept confidential?

All information you provide will be confidential and every effort will be made to ensure no individual is identifiable in any reports or publications. No information collected will be shown to anyone apart from those within the University and NHS involved in monitoring.

However if during the study itself, we become concerned that you or someone else may be at risk of harm, we would be obliged to inform a professional involved in your care. This is important to ensure you get the support you need.

What are the possible disadvantages and risks of taking part in this research?

You may find talking about your experiences distressing. You can choose whether or not to discuss certain aspects of your experiences and you can stop the interview at any time. If you do feel upset you can speak to the researcher or you can contact your MS Nurse, GP or Dr. Claire Isaac (Clinical Psychologist) who is supervising this research.

What are the possible benefits of taking part?

Some people find talking about their experiences helpful and enjoy the opportunity to voice their opinions. Whilst we cannot promise that this research will help you directly, it may help to raise awareness of the issues faced by those with MS and influence future service development and provision.

What if I want to complain about the study?

If you have any complaints or concerns about any aspect of the study, you may wish to consider sharing these directly with the researcher or research supervisors: Dr. Claire Isaac (0114) 2226639 or Dr. Sue Walsh (0114) 2226567.

If you wish to complain formally, you can do this through the NHS Complaints Procedure, please contact the Patient Services Team (Tel: 0114 271 2400; email PST@sth.nhs.uk). Alternatively, you can use the University complaints procedure by contacting Dr David Fletcher by post (Registrar & Secretary's Office, University of Sheffield, Firth Court, Sheffield, S10 2TN), telephone (0114 2221100) or email (D.E.Fletcher@sheffield.ac.uk).

Who is organising, funding and insuring the research?

The research is being undertaken as part of an educational qualification (Doctorate) in Clinical Psychology. It is funded and insured by the University of Sheffield.

Will I need to pay for my own travel?

The cost of public transport to and from sessions will be fully reimbursed; car drivers will be reimbursed at the rate of 40p per mile.

What will happen to the results of the research study?

All participants will be offered a copy of the results and there will be an opportunity for participants to offer feedback. The results will form part of a final report which will be submitted for publishing.

Who has ethically reviewed this project?

The study has been granted NHS ethical approval by Bradford Regional Ethics Committee. This means the research has the necessary procedures and safeguards in place to protect the rights, safety, dignity and well-being of all participants.

CONTACTS FOR FURTHER INFORMATION

Researcher: Joanna Blundell Jones, Trainee Clinical Psychologist, Clinical Psychology Unit, University of Sheffield, Western Bank, Sheffield, S10 2HP. Email: pcp09jkb@sheffield.ac.uk
N.B. If you wish to speak to the researcher please leave a message with the Research Support Officer on (0114) 222 6650 and the researcher will return your call at the earliest opportunity.
Supervisors: Dr. Claire Isaac, Clinical Neuropsychologist, 12 Claremont Crescent, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF. Tel: (0114) 2713770.
Dr. Sue Walsh, Clinical Tutor Lead, Clinical Psychology Unit, University of Sheffield, Western Bank, Sheffield, S10 2HP. Tel: (0114) 2226567.

This information sheet is for you to keep. Thank you for your time and help.

Appendix F

Participant Consent Form

 <p>The University Of Sheffield.</p>	<p>Department Of Psychology. Clinical Psychology Unit.</p> <p>Doctor of Clinical Psychology (DClinPsy) Programme Clinical supervision training and NHS research training & consultancy.</p>
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Participant Consent Form

Title of Research Project: Understanding emotional distress in Multiple Sclerosis: a qualitative study.

Name of Researcher: Joanna Blundell Jones

Participant Identification Number for this project:

Please initial box

1. I confirm that I have read and understand the information sheet explaining the above research project and have had the opportunity to ask questions and had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical or legal rights being affected. In addition, should I not wish to answer any particular questions during the interview, I am free to decline.
3. I understand that anonymised data collected during the study may be looked at by individuals from the University, regulatory authorities or the NHS Trust for monitoring purposes. I give my permission for these individuals to have access this data.
4. I agree to my anonymised responses being quoted in the research paper including if the paper is published.
5. I agree to take part in the above research project.
6. I agree to the researcher contacting me for my views on the results.

Name of Participant Date Signature

Lead Researcher Date Signature

To be signed and dated in presence of the participant

Copies: Once signed by all parties the participant should receive a copy of the signed and dated participant consent form, the information sheet and any other written information provided to the participants. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix G

G1 – HADS

N.B. The HADS has been removed to conform to copyright requirements

G2 – Guy's Neurological Disability Scale

N.B. The GNDS has been removed to conform to copyright requirements

G3 – GIQ

General Information Questionnaire

1. Age _____ 2. Sex Male Female
3. Ethnicity _____
4. MS Diagnosis
 Relapse Remitting Chronic Progressive Don't Know
5. If 'Progressive' MS, do you know what type?
 Primary Progressive Secondary Progressive
 Don't Know Not applicable
6. First symptoms: 19__ / 20__ Diagnosed: 19__ / 20__
7. Last symptom flare up:
 1 week 1 month 3 months
 6 months 12 months Over 12 months
8. Are you currently receiving treatment for a nervous or emotional problem?
 Yes No If yes, what is the problem?
-
9. Who have you seen / are you seeing for the problem?
 GP Counsellor Psychologist
 Nurse Psychiatrist Other (please state).....
10. Have you experienced low mood in the past? Yes No
 If yes, roughly when was this? For how long?
-
11. Did you receive any treatment for previous low mood? Yes No
 If yes, please give details (medication, therapy).....
-
12. Are you currently on any medication?
 Please state Medication Name/Dosage:

-
-

Appendix H

Interview Schedule

Interview Schedule – revision following 001*1. Theme – lived experience / daily impact of MS*

...could we start by talking a bit generally about what living with MS has been like for you, would that be ok? **Prompt:** perhaps start with when you first received a diagnosis?

Can you describe the impact of MS has had on your life? What's it like day to day?

Prompt: What is life like currently?

Prompt: relationships/family, work, physical, identity, social, general functioning, faith.

Prompt: How is it different to life before? How has the impact changed over time?

2. Theme – experience of emotional distress in MS

...let's talk a little more about the emotional impact MS has on you...

Can you describe how MS impacts on your mood?

Prompt: What feelings do you experience as you live with MS?

Prompt: Are there times when you feel better/worse? When does it happen? Can you describe the phases or the cycle of your experience if there is one?

Could you tell me a little bit more about what the emotional distress you experience is like? **Prompt:** What it's about? What do you think about?

What's your explanation for the distress/mood difficulties you experience?

Prompt: How do you understand why you feel...low / anxious? What's your theory?

Prompt: Dichotomy? Caused by neurological changes / psychological reaction to illness and illness-related changes

3. Theme – coping / treatment seeking

How have you coped with what you experience, on a day-to-day basis?

Prompt: What do you need when you're upset?

Prompt: Keep it secret? Share it? With whom? When?

Prompt: What things help? What things make it worse?

Prompt: family, friends, GP, MS Clinic, others, faith, alternative / complementary therapies

Generally what's been your experience of services helping you to cope with your needs? **Prompt:** physical, emotional

What do you do /would you do when very distressed?

How would/do you feel about going to see someone about your distress?

Prompt: How does that differ from seeking help for a physical difficulty?

Prompt: How would you know when you needed to help to cope with your distress?

What would help or hinder the process of seeking support/help?

4. Final question

Are there any other things you feel you've not had a chance to cover?

Appendix I

II – Annotated Transcript

J Blundell Jones
 Emotional Distress in Multiple Sclerosis
 003
 Transcriber Sarah Fox

Descriptive
 Linguistic
 Explanatory

1 I Okay so if we could just start off by talking a bit generally about
 2 what living with MS has been like for you if that would be okay? I
 3 mean you could start from perhaps when you first received the
 4 diagnosis, just for kind of general?

Impact of
 diagnosis

5 P003 Yeah erm, so when I was diagnosed nine and a half years ago
 6 erm, which was very... I don't know, it was a very chaotic thing
 7 and it just felt, erm, part of the, erm, sort of impact of it was the
 8 uncertainty of the future, erm and, (PAUSE) erm. And it just felt
 9 like someone had plonked the weight of the world on your
 10 shoulders, and I was twenty, four when I was diagnosed so it was
 11 just like, I was no longer young and carefree, you know. So, that
 12 was difficult and then... I think a lot of the sort of day to day *dealing*

Diagnosis chaotic
 not managed well?
 Uncertainty
 -not knowing
 + huge weight
 left there, felt like
 a huge thing
 no longer + aged

Lucky symptoms
 subtle

13 with it, is kind of erm, I suppose there's the physical aspect which
 14 doesn't really effect me that much, I'm very lucky that my
 15 symptoms are fairly, subtle, and erm, there's always the whether
 16 or not to tell people. And when I meet someone, it's up to me but
 17 it's such a part of who I am now, that's it's like, if someone really
 18 wants to get to know me they really need to know that. And then
 19 how you tell someone is part of that, because it's quite a big deal
 20 and... I don't know, it's quite, it's difficult isn't it to, just plonk that
 21 on somebody and then, how do they react. It's just a whole
 22 complicated issue of how people react because, I really don't take
 23 very well to kind of, pity and sympathy, and I just find that really
 24 patronising.

Lucky, subtle
 physical impact
 Disclosure bigger
 choice part of me - identity
 but if I want them to
 they need to know
 - how will they react

Identity
 disclosure +
 reactions of
 others.

Don't like pity
 or sympathy

Process of
 coming to terms

25 So I don't know, it's been just a ... still really it's coming to terms
 26 with it I suppose. I completely appreciate that I think it will
 27 probably take my whole life to come to terms with it... I don't think
 28 there will ever be a point when I can say "okay I've dealt with that
 29 and now I can put it behind me" because it's always there and it's
 30 always changing (yeah). And it's always kind of in the background

on a journey
 coming to terms
 will never have
 "dealt with it"?
 Changeable nature

Changeable.

often hidden
 until flare-up

31 so I don't ... it's not like I'm thinking about it all the time, but I'm
 32 aware of it all the time. But, you just hope, most of the time it's just
 33 hidden away in the background until, when I have like health flare-
 34 ups and stuff but that's not very often. But I don't erm worry about
 35 the future too much which I think, is useful (LAUGH) because, if I

Always aware
 but hidden until flare-up
 not frequent so hidden
 most of the time
 Good I don't worry
 too much.

I don't worry
 about the future

Appendix I

I2 – Emergent themes

Impact of diagnosis
 Lucky, symptoms subtle
 Identity
 Disclosure / reactions of others
 Process of coming to terms
 Changeability
 MS often hidden until flare-up
 Don't worry about the future
 Not just MS
 Physically not too bad
 Changes in symptoms make me angry
 Get on with life, forget it
 Comparison with boyfriend: ill-healthy
 He doesn't understand, feels guilty
 Disclosure and intimacy
 Work style fits with MS
 Wouldn't manage proper job
 Getting slower but still coping
 Sensory symptoms, not disabled
 Emotional impact of fall
 MS uninvited guest
 MS part of me and it's changed me
 Benefit-finding
 Part of me but unwanted
 Avoiding MS identity
 Won't let it define me

Not letting it win
 "I'm still me"
 Impact MS versus personality on social life
 Mood varies influencing sociability
 Do what I want but tire quickly
 Hold back to conserve energy
 Won't let it stop me
 MS coloured my world view / coping
 Unlucky I got MS
 MS affected my personality
 Balance: self-care and seizing the day
 Greater appreciation of health
 Mother's reactions unhelpful
 Anger at having MS
 Less patience with others
 Cancer, at least some certainty
 Frustration if it stops me
 Comparison to healthy others
 Loss of healthy future
 Anxiety about the future
 Live in the moment, avoid thinking too much
 How I cope varies
 Relapses consume me
 Calmer when well, get on with it
 Uncertainty with coping
 "Can't do" is distressing

 = me identity

 physical
 = impact of intruder

 = explanation for coping / mood

 = coping
 = simile / what want

 = feelings
 = what influences feelings

 = others

Tiredness and distress
 Take a step back to avoid spiralling down
 Unable to cope / alone (distress)
 Independence gone / can I rely on others? (distress)
 Loss of control
 Take a step back
 Emotional response to dealing with MS
 MS made me more emotional (I'm changed)
 Learning to cope (with emotions)
 Write to get thoughts out
 Don't share deeply with friends (avoid burdening)
 Questioning food etc?
 Pushed it to back and got on
 Fall knocked me
 Questioning coping
 Ignored it, pretend not there
 Bladder a reminder it's there
 Questioning coping
 Feel lost in sea of emotions
 People's responses unhelpful
 Feel helpless
 Someone who knows
 Learnt to step back, to avoid sliding down (yoga)
 Independence - self reliance
 Service support: physical versus emotional
 Emotional neglected

Diagnosis - hold it alone
 Hard to access psychological help
 Emotional side hardest to deal with
 Diagnosis - uncertainty
 Friend group could not relate
 Want someone who understands but depressing to talk
 Distract myself, avoid thinking
 Open to consider support
 Say things out loud
 Help organise thoughts
 Help to think differently
 Really sinking in
 Acceptance
 Still keep secret from others
 Help-seeking: physical versus emotional
 Emotions personal
 Hard to talk about feelings
 If consistently unable to cope, would seek support
 Physical deterioration, too much
 Support needs to be offered
 People need to be more open
 People can be dismissive
 Importance of time and location
 Adaptation "new normal"

Appendix I

I3 – Excerpt from Individual Theme Table

Version 4: 003	Main theme	Sub themes	Description	Evidence
1. Impact on me	a) Life stage and impact of diagnosis	Overwhelmed by unpredictable and uninvited guest. Stolen "youth" and changed outlook	<p>1:5-6 "when I was diagnosed nine and a half years ago erm, which was very... I don't know, it was a very chaotic thing"</p> <p>1:7-8 "sort of impact of it was the uncertainty of the future"</p> <p>3:101-102 "it is like an uninvited guest, that is what it, it's described like that. And it is, it's just kind of thrust upon you"</p> <p>1:8-11 "it just felt like someone had plonked the weight of the world on your shoulders, and I was twenty, four when I was diagnosed so it was just like, I was no longer young and carefree"</p> <p>6:177-180 "I was diagnosed quite young, comparatively, you know I was still learning about the world and growing up so, it's definitely coloured my view of how the world is"</p>	
	b) Changed self	Tension: it's part of me but not letting it define me. It has altered me.	<p>1:17 "it's such a part of who I am now"</p> <p>4:103-104 "but then, now it is, very much integral part of who I am"</p> <p>4:120-121 "I don't want it to define me, although it's part of who I am"</p> <p>4:114-115 "I think but then it is very much part of who I am"</p> <p>4:127-129 "even at the beginning I was like "I'm not going to let this win and I'm not going to let it define me"</p> <p>4:121-122 "I'm not just a person with MS, there's other stuff going on"</p> <p>4:104-106 "I'd be, probably, quite a different person maybe with a different outlook on, erm, life generally, how to cope with things, if I didn't have it"</p> <p>4:107-109 "it has benefits because, cos I'm a much more mature, calmer person, I think. Wiser person, because I've had to deal with this"</p> <p>6:180-181 "it's maybe made me a bit more... erm, more... stoic"</p> <p>6:198 "I think I'm more serious than I used to"</p> <p>11:343-344 "I think, since having MS, I have been more of an emotional person"</p>	
	c) I'm not particularly disabled but	I can mostly do what I want to do. But symptoms threaten my independence.	<p>1:13-14 "there's the physical aspect which doesn't really effect me that much"</p> <p>1:14-15 "I'm very lucky that my symptoms are fairly, subtle"</p> <p>1:33-34 "hidden away in the background until, when I have like health flare-ups and stuff but that's not very often"</p> <p>3:86 "I've had sort of occasional relapses"</p> <p>3:88-89 "they've mostly been, sense things, sense like sensations rather than actually disabling me"</p> <p>5:158-160 "I'm not particularly physically disabled, erm... I can pretty much do, what I want to do although I do get tired quite quickly"</p> <p>5:160-161 "it's like a, it's like a smart phone battery compared to like a regular phone battery. It's like my battery just drains really fast"</p> <p>6:168 "on the whole I do day to day stuff all right"</p> <p>3:71-73 "some days... I've got a massive headache or something because of, erm side effects of the, erm disease modifying therapy that I'm on"</p>	

Appendix J

J1 – Peer Audit Protocol

Protocol for peer audit of research findings

It was agreed by the peer supervision group that each individual could send a different transcript to each member of the group to be audited.

AIMS: To audit the data analysis process i.e. check themes are warranted and grounded in the raw data

To provide a means by which 40% of each researcher's analyses are audited

The researcher will provide each peer auditor with the following:

- Aims of the research
- A non-annotated transcript
- Annotated transcript
- Table of themes (including super-ordinate, sub and examples)*
- Any supplementary data necessary to see the link between the transcript and final themes e.g. diagrams, narrative summaries

*It is recognised that each researcher will have their own idiosyncratic way of presenting data.

Each peer auditor will follow the steps below:

"Engage in one thing with a reflective purpose, rather than lots of things with a corrective purpose" Larkin (2011)

- 1) Read the non-annotated transcript once to familiarise themselves with the data. Note down initial thoughts of themes, anything that stood out.
- 2) Read the annotated transcript and table of themes once – be observant of any sections completely missed (i.e. no emergent themes noted).
- 3) Work through 10% of the transcript length (section chosen by auditor), checking the method used to obtain themes
 - Has the theme come from the data, yes or no?
 - Does a label or theme seem directly related to a theory rather than coming from the data?
 - Is the account coherent & plausible? Could anything be clearer?
- 4) Discuss thoughts from the process with the researcher especially any additional ideas on anything of interest/importance they may have missed.

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Appendix J

J2 – Summary of Feedback on Themes

Expert Auditors

One expert auditor noted that the initial themes were too concrete, too focused on detail which meant the emotional story was missed, e.g. the sense of loss and pain was too hidden. The researcher went back to the data and looked for the meaning and significance of the experiences shared. The other expert auditor noted that although all themes made sense, they queried whether the themes were too negative in focus. This made the researcher notice a bias towards focusing on difficulties and she went back to the data to consider the value and importance of coping in the narrative.

Peer Auditors

All peer auditors affirmed that themes were grounded in the data however they felt interpretation of themes could be deeper. One suggestion was that coping strategies could be given further interpretation, e.g. writing out thoughts can be seen as a form of emotional expression or control; minimising and normalising may sometimes be an expression of having difficulties with acceptance. Peer comments helped the researcher to develop skills at getting to the essence and meaning behind what was said.

Respondent Validation

Both participants reported that their experiences were captured in their individual themes and in the group themes. One participant queried whether coping strategies could be emphasised more. This was indicative of her overall coping strategy of always wanting to minimise the negative and enhance the positive. Given that a lot of the interview narratives focused on sharing the difficulties and hardships of living with MS a decision was made not to adjust the emphasis until feedback from more participants was received.