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Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition

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the part of the primary caregiver, usually a close family relation, will change over time [12]. Social and family support has consistently appeared throughout the literature on rehabilitation and adjustment to disability [13] and has been identified a salient factor in an individual's adjustment to MS [9,11,14,15].

Wineman previously suggested that, regardless of functional ability, an individual's perception of uncertainty and social support may contribute to adjustment in MS [9]. At any time the course of the disease can shift [16], thus individuals live with uncertainty every day and this is a major challenge for them [17]. Furthermore, high levels of uncertainty are related to negative emotional outcome, such as depression and emotional distress [9,16]. Success in coming to terms with uncertainty may have a salient impact on individuals' psychological adjustment to the disease [9,17,18]. However, the construct of uncertainty and its psychological consequences in relation to adjustment has received little attention in the literature [17].

Psychosocial adjustment to MS can be understood as the ability to foster a positive outlook on life, continuing to grow and develop in spite of MS [19]. As such, individuals with chronic disease who successfully experience psychosocial adjustment generally strive continuously to control the physical symptoms, adjust to role changes and maintain a positive self-concept [20]. Many studies have investigated the psychosocial impact of, and adjustment to, disability and MS. In their review of the literature on psychosocial adaptation to disability by people with MS, Antonak and Livneh begin with a general discussion of the various aspects of adaptation to chronic illness and disability: reaction phases; instruments to measure adaptation and the research required to construct a theoretical model of the process [21]. In their review, Antonak and Livneh reported that there is little agreement on the nature of the concept [22]; indeed, some investigators have analysed data on demographic, personality and illness-related variables and reactions to MS [9,11,22], whilst others have conceptualised reaction and adjustment to MS as an adaptation process [23] which may consist of temporarily ordered phases including denial, resistance, affirmation and integration [24,25].

Another perspective on reaction and adjustment to MS emphasises aspects of self-perception and appraisal. As MS is unpredictable in its disease course and has a wide range of potentially disabling effects, individuals face confusion in assessing the disease and its impact on their lives [26]. Strong signals from the body, emotions and reactions of other people are likely to elicit a re-examination of who one is and what one is worth [25].

An important line of research to date, therefore, has focused on self-concept and identity as salient aspects of the adjustment process. Indeed, self-efficacy has also been identified as a predictor of self-esteem and later behavioural outcomes for people with MS [27]. However, self-concept and self-esteem are more often viewed as dependent variables; in a longitudinal study investigating four sets of variables in relation to adjustment, self-concept was used as a measure of adjustment [25]. Furthermore, shifts in self and identity have also been reported to be closely related to love [28] and constructions of sexuality for women living with MS [29,30]. Demoralisation and deterioration in relationships have been identified as psychosocial effects of having the disease [30]. A recent study by Boeije et al. reported that many 'salient aspects of self' were lost as a consequence of having MS [31], i.e. one's concepts of self as active, independent, providing for others and capable of paid employment are supplanted by negative self-concepts.

Only those with a firm perception of 'personal control' are able to maintain self-esteem [32]. The beliefs that persons with MS have about the disease have been reported as having a significant role in adjustment, even when the effects of the severity of the disease are taken into account [33]. Because the majority of people with MS experience recurrent remissions and exacerbations, identity issues and re-evaluations of self may be ongoing [11,34].

Importantly, self-concept and identity issues, including values, beliefs, and perceptions of self and are not always negative outcomes of living and coping with MS. Brooks and Matson previously reported a small positive alteration in self-concept for those individuals diagnosed for at least 8 years [25]. The authors concluded that, following initial adjustment, self-concept tends to become more stable over time and that the process of adjustment, which tends to take place in the first ten years following diagnosis, is relatively positive for people with MS. Also, Mohr et al. reported that people with MS can experience psychosocial benefits as a result of their disease which they refer to as 'Benefit-Finding' [35]. This reflects a deepening of relationships with others, an increased appreciation for life, and an increased focus on spirituality attributed to having MS.

Becoming ill or disabled is recognised as one of several major identity transitions that a person in contemporary society may have to engage in during the lifecycle [36]. Indeed, Boeije et al. recently suggested that 'coming to terms' with, and accepting, MS may involve 'identity reconstitution' [31]. Given the salience of identity, appraisal of self and representation of the illness, and the need for further insight into these aspects of adjustment, this study explored individuals' subjective experiences of

coping with the changes associated with MS and the adjustments required in relation to self and identity.

Method

A semi-structured focus group interview methodology was employed in this study in order to facilitate interactions between participants about their experiences. Focus groups are guided discussions that enable researchers to gain a rich understanding of participants' beliefs and experiences. Furthermore, the exchange and interaction between focus group participants can reveal issues that the researchers may not have previously considered. A list of themes for the focus group interview was derived following an extensive review of the literature. Ethical approval was obtained from the University of Ulster's Research Ethical Committee.

Participants

Participants for the focus group interviews ($n = 8$; 7 females, 1 male) were identified using purposive sampling techniques [37] and included members of a branch of a local MS charity who were invited to participate if they fulfilled the following criteria:

- over 18 years of age
- had been diagnosed with MS for at least 5 years
- willing and able to participate in focus group interviews

It was anticipated that individuals with at least 5 years since diagnosis would likely have reached a stage at which they were ready to openly talk to a group of people about their experiences. This duration was based on research which indicated that ongoing psychosocial effects are experienced within two years following diagnosis [22] and that major psychosocial adjustment tends to take place in the first 10 years [24].

Characteristics of the focus group participants are presented in Table I. There were eight participants, 7 females and 1 male. The age range was 36 to 63 (mean age = 49). The number of years since diagnosis ranged from 5 to 20 years (mean = 12.8 years), however one participant omitted to provide this

information. Years spent in education ranged from 10 to 19 years (mean = 13.4). One participant was a full-time homemaker and had been all her life, whereas one participant had retired prior to being diagnosed with MS; the others had been previously employed but have had to give up paid employment as a consequence of MS. Six participants were married, one was separated, and one was divorced: in the case of the separated participant, there is no information on when the separation took place and the divorced participant revealed that her husband initially agreed to support her after she had been diagnosed but eventually left her and they later divorced. Six participants had children, five of these had two children and one had three children.

Procedure

The focus group was conducted in March 2004 in a location normally used by members of a local MS charity for social activities. To accommodate the participants' lifestyles, the discussion took place in the early evening. The seating arrangement was circular in formation and refreshments were provided. The researchers began by introducing themselves and giving a brief synoptic account of the background to the study. Participants were then asked to complete a form requesting the following demographic information: name, age, gender, years since diagnosis, years spent in education, employment status, marital status and number of children.

The session was undertaken by two researchers, one of whom facilitated the group discussion and the other acted as note taker. With the participants' permission, the session was audio recorded. Participants were asked to briefly introduce themselves, stating their name and a favourite movie, so that their voices could be identified on the tape during transcription. Name badges were used so that the moderator could refer to participants by name and to facilitate the recording of notes.

Discussion points were introduced as open-ended questions and, where appropriate, participants were asked to elaborate on their responses and were encouraged to exchange views and revelations between themselves. Discussion revolved around the problems and feelings associated with MS and how these affect day-to-day life, their values and beliefs and how they see themselves. Participants were given the opportunity to mention any relevant points that had not been covered in the focus group at the end of the discussion. The note taker documented the main discussion points, verbatim examples of the dialogue and non-verbal communication. During and immediately after the focus group discussion, the researchers recorded fieldwork notes. These notes recorded information that would

Table I. Characteristics of focus group participants.

Gender	Female, 7; male, 1
Age	Range, 36–63; mean, 49
Marital status	Married, 6; separated, 1; divorced, 1
Children	Two children, 5; three children, 1; no children, 2
Years since diagnosis	Range, 5–20; mean, 12.8
Years in education	Range, 10–19; mean, 13.4
Employment status	Unemployed ($n = 7$); retired ($n = 1$)

not be available from the transcribed tapes such as seating arrangements and body language; these details helped the researchers to interpret the meaning of the participants' words accurately. Following the focus group discussion, the researchers transcribed the tape verbatim and recorded all major themes where an interpretive phenomenological analysis approach [38] was adopted to gain an understanding of the participants' experiences of adjusting to MS. Each of the two researchers independently read the transcript in its entirety several times. A third researcher, not involved in the focus group session, independently read the transcript and determined themes. The research team then met to compare analysis and worked to reach a consensus on the key themes that emerged. Once these themes were identified and agreed, a summary was sent to all participants for verification, to ensure that all themes identified were accurate. For the purpose of protecting anonymity, participants were identified only using an initial where necessary.

Results

In depth reflection and discussions by the research team resulted in the emergence of the following key themes: reaction to, and impact of, being diagnosed with MS; social activity; role in society and self-worth; relationships and dependency; attitudes and reaction of others, and finally, perceptions of adjustment and changes in self-concept, identity and outlook.

Reaction to being diagnosed/impact of being diagnosed with MS

Initial concealment upon diagnosis was evident. One participant revealed that when she was diagnosed with MS she refused to disclose this to anyone for a number of months. Another told of how she was 'completely devastated' when she was first diagnosed, and how she ignored the illness at first. This participant refused to tell anyone of her diagnosis and thought that no one would notice. She believed there was a stigma attached to MS and did not admit it, even to her own children until 'she had to'. She told of how, when her children discovered she had MS, her son had ripped the disabled sticker of her car and proclaimed 'people will see that'.

A number of participants reported that their diagnosis had adversely affected their confidence. One participant reported that when she was diagnosed she was just told to 'go away and live with it', which she found very upsetting. Another, who had previously had a busy working life and is now a wheelchair user, reported that it had been extremely

detrimental to her self-confidence; the disease 'robs you of your confidence'.

In contrast, one participant told of how her husband looked upon the diagnosis of MS positively because it was initially suspected to be 'something worse – a tumour on the spine or motor neuron disease'. His positive outlook made her feel better about the diagnosis and gave her hope. However, she also said that after being diagnosed, for the first 6 months, her husband washed and dressed her before leaving for work because she did not want anyone else to do these things. She perceived that it was hard for her husband because she was not the 'girl he married anymore'.

All participants indicated that uncertainty about the future was disconcerting. This was most evident where they indicated that they do not plan for the future, e.g. they do not plan holiday months in advance as they do not know how well they will be at that time. Many expressed fear or concern about the future. One participant, who was diagnosed with primary-progressive MS, said the symptoms are 'gradually going to get worse' and that 'it is a battle every day'.

Social activity

When first diagnosed, participants were advised to go to (MS charity) 'clubs' but they were reluctant to in case they 'saw people in wheelchairs'. But now they love the 'clubs', as 'everybody understands and everybody knows'. Most of the participants said that they were 'never in' (out of the house, regularly attending the MS group meetings), and one participant claimed that her husband 'speaks more to the answering machine than to her'.

The majority indicated they were often 'out and about', but one participant added that she 'avoids crowded places'. The majority of participants agreed with this, indicating that they go shopping early in the morning to avoid crowds. One participant commented, 'once you admit to yourself, you make your life suit you and you don't let life pass you by'.

One participant disclosed that she constantly apologises to people in the street, sometimes when she has not done anything wrong. A number of others agreed with this and said they are always apologising for bumping into people when out in public. In an attempt to overcome this, one participant indicated that when shopping in a supermarket, they use a trolley to protect them from colliding with others. A small number disclosed that they felt clumsy when paying for products with loose change. They admitted to keeping their money in their pocket, rather than in their purse, in an attempt to alleviate this.

Role in society and self-worth

The majority of participants had to leave paid employment due to the symptoms associated with MS, particularly fatigue, and had regrets about this. One participant had owned a hairdressing business and remarked that she could not carry on because she was standing all day, normally in high heels. This provoked a strong reaction from the rest of the females in the group who indicated that they missed being able to wear high heels or 'strappy sandals'. One participant indicated that she can only wear flat shoes, saying, 'it's the things it (MS) takes away from you'.

Another participant had to leave paid employment because of eyesight problems. Although she stressed that her employers were very understanding and provided frequent breaks, she felt as though she was 'stealing from them'. In the end she left because she did not think she could do her job as well as someone else could, and thought this was unfair to her employers.

However, it was not only the loss of paid employment that the participants regretted. One participant mentioned that another aspect of her 'working life', housework, and specifically ironing, was problematic. Because of fatigue she could no longer do this and had a private arrangement with two of her friends to assist her. She is now in the position that she can do some of her own housework and, although it takes time, she appreciates it so much more and 'thanks the Lord that she is able to do these things'. Another participant added that she is delighted that she can iron her husband's clothes now as a result of adaptations, because it was 'so long when you couldn't do those things'. She commented, 'when the power comes back, when you are having your good times, you just want to do things'. Thus, although participants recognised that changes had taken place since diagnosis, the majority of participants felt they still had a place in society and could achieve a sense of accomplishment.

Relationships and dependency

Dependency and support from others was an issue that participants felt impacted relationships. The majority of participants reported that their partners provided them with the most support; physical, emotional and financial. Of the two participants who were divorced, one reported that her children gave her the most support and the other received support from her parents.

Dependency and negotiation of the degree of support needed for certain tasks seemed to be a source of tension in participants' relationships with those closest to them (their caregivers). The majority

commented that caregivers did not like to watch them do things and this caused frustration on the part of the participants because, even though the simplest task may take them twice the time, they still want to try to do it. One participant was frustrated when her mother did not 'allow' her to carry out tasks in the home to prevent her from tiring herself out. Another stated 'they (the caregivers) feel hopeless and useless, because they can't do anything for you'. This lady's husband did all the cooking and even though the participant appreciated his help, she said he often made comments which she referred to as 'a joke with a jibe'. This made her feel annoyed; even though she felt it was only a joke, it had an underlying reality. Other participants claimed that their caregivers were 'killing them with kindness'. This notwithstanding, they all reported that they understood how difficult it was for caregivers and some commented that being the caregiver of a person with MS was sometimes more difficult than actually having the disease.

Attitudes/reactions of others

The majority of participants felt that others often did not understand about MS, but that public awareness was getting better in that 'the use of wheelchairs has now been brought to the public eye more through television'. One participant commented that when you are a 'walker' and 'have a normal life, you don't want to think about mortality or other people very much . . . other people do not consider what it would be like to be unable to walk'. This participant commented that she would prefer it if people would treat her the same as everyone else; as a 'walker'. She commented that 'it embarrasses people because they don't know how to react'. She felt that everyone should be made to spend 1 week in a wheelchair to experience what it is like for her, so that they can empathise with her. This participant felt it would be interesting 'to see how they cope and to see how they relate to other people, and how other people relate to them'. Such a scenario was described when one participant shared her experience of an occasion where she was out with a couple who she and husband were only acquaintances with; they asked her husband if she took sugar, rather than asking her. She said to them 'although MS has affected my legs, I can still speak!' She said that 'it embarrasses people' and another participant echoed this comment. There was general consensus that other people feel uncomfortable or embarrassed and do not know how to respond to their situation.

A number of further concerns were raised surrounding the perception of 'walking'. One participant felt that other people perceive her as being drunk as she walks unsteadily and occasionally would

fall to the ground. She refuses to use a walking aid because she wants to continue walking on her own for as long as possible. Another participant felt that using a walking stick is more of a hazard than help. Another admitted that she would not be in as much pain if she 'gave in' to using her wheelchair however, she wants to stay on her own feet as long as possible, which is more to do with 'how it makes you feel and your pride'.

Changing outlook/perceptions of adjustment and changes in self-concept and identity

The majority of participants stated that they had, in time, 'learned to live with it'. Many indicated that their priorities and values had changed in a positive way; they appreciated and enjoyed simple pleasures, the little things in life that they took for granted before, 'you suddenly notice that the grass is green, whereas you didn't have time before'. One participant stressed that she is more appreciative of her life now than before as she had an extremely busy job; 'it's just an appreciation of everything ... I appreciate the smaller things, the quiet times as well'.

All the participants appeared very optimistic and content however, they did admit that when 'you catch them on one of their off days' things would look different. Fatigue was reported to impact on almost all aspects of the participants' day to day lives; 'you have to pace yourself ...', 'you get tired' and 'drained'. 'After a while you need to know what your limitations are'. One participant, who was very positive and claimed that she 'lived life to the full', admitted that some days are not so good. She said that there are times when she cries because her 'body is so heavy' that she cannot physically get out of bed.

One participant mentioned that those who have been recently diagnosed might see things differently than those participating in the focus group. Many of the participants agreed and commented that at the beginning they were not so optimistic, however this has changed over time. Reflecting on this, the majority of participants indicated that their outlook on life had changed. This was achieved by valuing life and living in the present, 'take every day as it comes' and 'enjoy life while you can'. However, one participant admitted that she was permanently on anti-depressants 'just to keep my spirits up'. 'It's just a part of the course ... you get depressed from time to time'. Another responded to this by commenting that rather than getting down, she 'lived for today because tomorrow may never come'. Others in the group nodded in agreement with this comment; 'living for today' was perceived as a way of coping with uncertainty.

Continuing on a positive note, one participant felt that she has become a 'much nicer person' now that she is a wheelchair user. This participant reported

that she has found faith in God since developing MS, and believes she was 'put into a wheelchair for a reason', that she was 'being knocked down to size'. She indicated that God had approached her so many times before and she refused him because she did not have enough time, as she was so busy with work. She is sure that she will be walking again because God will help her. The majority of participants felt that 'faith in God gets you through'. However, one participant shook her head in disagreement although she chose not to make any comment.

Thus, although diagnosis was met with negative reactions such as denial, concealment and diminished confidence, over time many of the participants reported that there were positive changes in terms of their values and outlook. It seems that the functional difficulties and psychological challenges such as uncertainty and depression that can accompany the disease are compensated for, to some extent, by an increased appreciation for life and spirituality.

Discussion

This focus group discussion allowed individuals with MS to reflect on their reactions to being diagnosed and the impact of the disease on their lives. They expressed, in their own words, how they cope with the day to day challenges of the disease, and the changes that they have experienced, both negative and positive.

The study provides evidence that MS has significant physical, psychological and social impacts upon the individual. When asked about the most troubling symptoms, fatigue was reported to impact greatly upon participants. All indicated that this symptom affects almost all aspects of their lives. Indeed, it has previously been reported that fatigue hinders continuous physical exertion, limits work and social activities and is associated with a poorer quality of life [39–42]. Furthermore, fatigue is reported to be the most significant factor in the high unemployment rate among people with MS [43] and was indicated in the current study to be the main reason for having to leave paid employment, which the majority had regrets about.

The loss of the financial and psychological benefits that are provided by paid employment such as a sense of purpose and worth, a structured day and social interaction, is reported to have a major impact on psychological well-being and also on identity, as individuals often describe themselves in terms of what they do for a living [14]. The findings from the current study support those by Boeije et al. who reported that many salient aspects of self were lost as a consequence of having MS [31]; one's concept of self as active, independent, providing for others and capable in employment are supplanted by negative

self-concepts. Nevertheless, a number of participants achieved a sense of accomplishment from performing household tasks which helped to maintain a sense of self-worth.

The relationship between the physical and psychological effects of MS is complex and potentially important to people with MS [9]. Having a diagnosis that causes the individual to be restricted physically, can inaugurate shifts in how one perceives oneself, resulting in changes in the social and sexual aspects of life [29]. The female participants in this study expressed regret not being able to wear to wear high heels, indicating a loss of femininity; 'it's the things it takes away from you'. This strong sentiment supports the contention that diagnosis can also have potentially negative consequences for an individual's body image and sexuality [30,44,45].

Findings also demonstrated the physical and psychosocial impact of MS not only in terms of what it takes away from the individual, but also in terms of their adaptation and adjustment. Initially, diagnosis was met with negative reactions; denial, concealment and diminished confidence. Such reactions indicate that this is a period of challenging internal transition; the individual is facing changes in how they see themselves and how others might see them. These findings, therefore, support the study by Janssens et al. which concluded that the adjustment process starts immediately following diagnosis and that clinical intervention and psychological support should be available at an early stage [22].

This period immediately following diagnosis appears to be one of identity crisis stemming from the dissonance associated with realising that they now have much in common with chronically ill people. This is in line with the evidence from other research which has indicated that disability and chronic illness can bring about substantial changes in the patient's identity [20,31,46]. Furthermore, with MS, uncertainty about how the disease will progress means that personal aspirations are curtailed and have to be reassessed.

The resolution of identity crisis that accompanies diagnosis requires changes in value and belief systems [47] and this was reflected in a changed, more optimistic, outlook as they 'learned to live with it' and came to value life and simple pleasures. They coped with uncertainty about the future by focusing on the present and 'living for today'. Also, with regard to positive personal change, one participant reported that she was a much nicer person and had found faith in God. These findings support other evidence of positive changes for people with MS including positive alteration in self concept [25] and 'benefit finding' [35,48].

Furthermore, many participants in the current study reported that, over time, there were positive

changes in terms of their values and outlook. It seems that the functional difficulties and psychological challenges such as uncertainty and depression that can accompany the disease are ameliorated to some extent by an increased appreciation for life. The focus on deficits in much of the existing literature on MS would suggest that positive outcomes of the illness and the experience of adjustment has been overlooked or under acknowledged. The findings in the current study would suggest that changes can be both negative and positive.

The study provides evidence that living with multiple sclerosis can affect various aspects of an individual's self-concept and identity resulting in 'an alteration of that person's sense of self in relation to the world' and the identity of a disabled person [49]. For this group, adaptation over time appeared to be mainly psychological and spiritual rather than physical. There are changes in values and beliefs, changes in relationships and identification with others, particularly those closest to them who may take on the role of caregiver, and also changes in how they perceive themselves and their perceptions of how they are viewed by others. Relationships with others, family and friends and, in some cases, a higher power, appeared to be a great strength in adjusting to the disease and the uncertainty of life with MS. Uncertainty about the future is a major challenge and has consequences for the aspirational self (one's aspirations towards being the kind of person one would like to be) another important element of self and identity [36]. These findings therefore support the proposition that self and identity are important in one's transition through health to illness [25], and supports the conclusion by Kralik et al. that self and identity are key concepts in understanding the experience of transition when living with chronic illness [30].

Although the major difficulties in rehabilitation of persons with MS are variability of the symptoms and the uncertain prognosis, the person's response to rehabilitative opportunities may be limited if he or she has not made a successful adaptation to the disease and its disabilities [21]. Key factors that influence the person's rehabilitation potential include perception of the disease, self-appraisal and relationships with others. Interventions that could help people with MS in the challenging process of role/identity re-examination and adjustment include positive assets interventions, encouragement to develop new interests, activities and relationships and also rational emotive therapy to challenge irrational or unfounded self perceptions [11,18]. By addressing identity issues in this way, healthcare professionals can help people with MS manage the disease and enjoy productive adult lives.

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