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### **Abstract**

This study explored women’s strategies for living with multiple sclerosis (MS). Twenty-seven women were interviewed, most of whom had lived with MS for more than five years. Analysis of the semi-structured interviews followed the interpretative phenomenological approach. The women portrayed living with MS as an ongoing process of negotiation, and described gaining quality of life through looking after their health; maintaining a familiar self-image, particularly through meaningful occupations, and adapting pre-illness skills and interests to their changing levels of physical functioning; actively valuing positive life experiences, including finding benefits in adversity; clarifying values, priorities and philosophy of life; and maintaining mutual, caring relationships. Some regarded MS as presenting opportunities for personal growth. Without minimizing the very substantial difficulties that MS presents, the findings suggest that well-being derives from both managing the illness and also embracing life’s wider experiences, including change and growth. Implications for rehabilitation and counseling professionals are considered.

## **“Sticking jewels in your life”: Exploring women’s strategies for negotiating life with multiple sclerosis.**

### **Introduction**

This paper seeks to explore the lived experience of MS, in particular focusing upon women’s personal strategies for achieving an acceptable quality of life. Gulick (1997) and Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, (1999) have pointed out that there have been few studies in this field. A chronic illness such as multiple sclerosis (MS) imposes so many losses upon the person and the family that to maintain satisfaction with life might at first sight be considered impossible. Indeed, compared with other chronic illnesses, MS is considered to be particularly threatening to psychological well-being (Rao, Huber & Bornstein, 1992; Rudick, Miller, Clough, Gragg, & Farmer, 1992). Moreover, in MS, the deterioration of mobility, visual acuity, sensation, continence and energy levels often follows an uncertain course, particularly in the more common relapsing-remitting form of the disease. Some research studies (and also personal accounts written by individuals with MS) suggest that uncertainty is one of the most difficult aspects of the disease to live with (Miller, 1997; Stuijbergen & Rogers, 1997; Webster, 1989). As with other serious illnesses, MS can be understood to provoke profound biographical disruption (Bury, 1982) through its effects on self-image, social roles, and valued occupations. For example, mobility problems, visual impairment and fatigue, together with unsupportive employer attitudes, push the majority of people with MS into early retirement from work within a few years following diagnosis (Hakim, Bakheit, Bryant, Roberts, McIntosh-Michaelis, Spackman, Martin, & McLellan, 2000; Jackson & Quaal, 1991; Lundmark & Branholm, 1996). Financial difficulties and social isolation may then ensue, creating additional stress and undermining self-esteem.

Some qualitative research studies and autobiographical accounts reveal profound grief and depressive reactions following the diagnosis of MS, in response to the perceived loss of a familiar self, valued leisure pursuits and social roles (Barton, Magilvy, & Quinn, 1994; Brown, 1984; Burnfield, 1985; Forsythe, 1988; Shuman 1996). Moreover, the difficulties of adjustment to the physical limitations of MS and the

maintenance of a positive self-image are rendered more problematic by negative social responses, including the tendency of others to misinterpret an unsteady gait as a sign of intoxication, and to disbelieve the 'reality' of illness, when symptoms fluctuate from day to day (Gordon, Feldman, & Crose, 1998; Webster, 1989). Yet there is also growing recognition that over time people may develop positive strategies of living with MS, and achieve levels of psychological well-being that they find acceptable (Lundmark & Branholm, 1996; Robinson, 1990) .

Quality of life is difficult to define and measure in objective terms, and does not seem to be a unitary experience. In addition, it appears that self-assessed quality of life is not simply determined by level of physical functioning, as many people with marked limitations of mobility and independence report positive satisfaction with their quality of life (Albrecht & Devlieger, 1999). So what experiences contribute to positive life satisfaction in illness? Evidence indicates that people (both with and without health problems) tend to regard their lives as of high quality when they can accomplish the goals that they consider most important (Goode, 1994; Stuifbergen & Rogers, 1997) and achieve their hopes and aspirations (Aronson, 1997). Webster (1989, p. 27) described her own challenge in the aftermath of diagnosis with MS as 'how to fashion a life which was lived fully and normally' whilst accommodating her needs and limitations. Various studies reveal that goals, hopes and aspirations are subject to change over the life course, and that chronic illness can lead to new priorities (Becker, 1997; McAdams, Josselson, & Lieblich, 2001; Weitzenkamp, Gerhart, Charlifue, Whiteneck, Glass, & Kennedy, 2000). Re-prioritising may allow people with chronic conditions to maintain their identity and self-esteem by focusing their efforts on activities that are both valued and also feasible within the limits of their functioning (Weitzenkamp et al, 2000).

Evidence also suggests that people with MS report more satisfaction with life when they have good emotional health (Nicholl, Lincoln, Francis, & Stephan, 2001), maintain valued roles, social relationships and family life (Barton et al, 1994; Stuifbergen & Rogers, 1997), engage in meaningful leisure pursuits (Hakim et al, 2000; Lundmark & Branholm, 1996; Kinney & Coyle, 1992; Patterson, 1984) and make a contribution to others (Barton, et al., 1994; Schwartz & Sendor, 1999). These

needs are not particular to disabled people but characterize positive human motivation more generally (Maslow & Lowry, 1998). Charmaz (1991) notes that some people with chronic illness prefer to engage in valued pursuits even at the expense of their health. For example, they are willing to risk profound tiredness or pain to play with their children or to pursue a valued hobby. Qualitative interviews by Barton et al (1994) with people who have MS confirm this observation. It is unclear how and why some people manage to retain roles and occupations in the face of illness, preserving a satisfying lifestyle, whilst others withdraw. A range of cognitive, emotional and practical coping strategies may be important. These include maintaining beliefs in personal accomplishment (Quinn, Barton, & Magilvy, 1995), increasing one's spiritual and philosophical perspective on life (Tedeschi & Calhoun, 1995), enjoying humor (Barton et al, 1994), as well as pacing activities, simplifying lifestyles, and setting manageable goals (Charmaz, 1991; Lundmark & Branholm, 1996; McLaughlin & Zeeberg, 1993).

Many studies of quality of life in MS has been based on questionnaire assessment (e.g. Gulick, 1997; Nicholl, Lincoln, Francis, & Stephan, 2001; Vickrey, Hays, Harooni, Myers, & Ellison, 1995). However, Stuijbergen & Rogers (1997) elucidated some of the subjective experiences that contribute to quality of life through qualitative interviews with people with MS. Participants stressed the importance of family relationships, functional independence, spirituality, work (paid or unpaid), financial security and self-actualization. The participants were active in maintaining their own physical health (through physical exercise, good nutrition, balancing rest with activity and so on) but regarded quality of life also as enhanced by access to wider life experiences, and a continuing commitment to positive growth. Similarly, 'evolutionary growth' was also regarded as a priority by people with MS interviewed by Quinn et al (1995). Personal growth motives have also been noted in qualitative studies of people living with other chronic conditions. For example, Crossley (2000) reported that some people with HIV/AIDS described their illness as a stimulus for personal growth and self-actualization. The illness experience had resulted in a reappraisal of goals and values. Energy and time were as a consequence devoted to the activities and goals that mattered most to the person, including relationships, creativity, and making a lasting contribution to others.

A variety of recent qualitative and quantitative studies indicate that some people achieve well-being through learning to find benefit in adverse life experiences such as serious illness. Antonovsky (1990) has argued that people maintain a sense of coherence (in itself important for health) through believing that their circumstances are meaningful, manageable and that something of value can be gained from living through their difficulties. In a similar vein, it has been observed that highly generative people narrate their lives in ways that focus on the good consequences that can follow on from difficult life events (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001). Some people even come to interpret life-threatening conditions as a 'blessing' through valuing a heightened sense of authenticity, and the more honest, caring relationships that they experienced as a result of illness (e.g. Affleck et al, 1987; Reeves, Merriam, & Courtenay, 1999; Young and McNicholl, 1998). Charmaz (1991) described people with chronic conditions as living in the 'intense present', making the most of their opportunities. "With the intense present comes a sense of urgency – urgency to act, to experience, and to bond with other people" (p. 246). Mohr et al (1999) put forward the term 'benefit-finding' to describe such coping strategies such as valuing the close relationships achieved during illness, and positive reinterpretation of current circumstances. Likewise, Robinson (1990) noted similar themes in more than half of the written narratives that he received from people with MS, He referred to such narratives as 'progressive' in that they conveyed beliefs that valued life goals could still be accomplished even in the context of illness. Many autobiographical accounts written by individuals with MS also emphasize certain 'gains' from the MS experience, including empathy with others who are less fortunate, satisfaction gained in helping others, stronger family relationships and friendships (Brown, 1984; Burnfield, 1985; Lowry, 1984). Similar perceptions of gain appear in the accounts of people with other serious illnesses such as cancer (e.g. Breaden, 1997; Thibodeau & MacRae, 1997).

It appears that positive interpretations of the illness experience are rarely achieved in the immediate aftermath of diagnosis when feelings of shock, grief and even terror often predominate (Barton et al, 1994; Webster, 1989). Positive reinterpretation, benefit-finding and a 'fighting spirit' seem to be associated with the later stages of adjustment to illness. Nevertheless, it is important not to conceptualize adjustment as a simple, linear process. People's stories of living with chronic illness incorporate

both negative and positive themes, and their acceptance may fluctuate over time (Sanders, Donovan & Dieppe, 2002; Yoshida, 1993). Negative attitudes and emotions may surface again, particularly in response to worsening symptoms, loss of a supportive relationship or other negative life events. Good days and bad days are a common feature of chronic illness (Charmaz, 1991; Webster, 1989).

The studies reviewed suggest that many people with MS (as with other illnesses) devise certain positive strategies for living with illness, and manage to achieve a personally acceptable quality of life, yet it is nevertheless important to avoid promulgating culturally sanctioned values about the desirability of the 'fighting spirit', the value of 'doing' over 'being', or the obligation to pass as 'normal'. Disabled people describe feeling judged as 'less of a person' if they are not stoical and accepting of their impairments on the one hand, or battling for a 'cure' on the other hand (Radley, 1993). It is vital for researchers to be mindful of the values that they may unwittingly impose upon participants' own stories, and to listen carefully to the views that participants express.

### **Study Purpose**

This study sought to gain further insights into women's strategies of living with MS, and the experiences that promote satisfaction with life. The review of research and autobiography in this field establishes that a variety of cognitive and emotional coping strategies help some people with MS to maintain well-being and resist depression. This include positive reinterpretation, priority shifting and comparing the self with others who are more disadvantaged, The review also suggests that social relationships, the experience of contributing to others, pursuing valued goals and meaningful occupation (whether paid work or recreational activity) also enhance quality of life for people with MS (in the same way as these experiences provide fulfillment for people enjoying good health). Yet some studies purporting to examine the role of roles and occupations in maintaining subjective quality of life with MS only measure the frequency of participation in different activities by people with MS rather than their personal value and meaning (Eklund & MacDonald, 1991; Finlayson, Impey, Nicolle, & Edwards, 1998; Lundmark & Branholm, 1996). Therefore this study not only explores emotional and cognitive coping strategies but seeks to understand women's wider strategies for living an acceptable life in the context of

MS. Special consideration is given to the roles and occupations that fill daily life in satisfying ways. Shuman (1996), a doctor with personal experience of MS, argues that “there are those who knit together well-made lives out of the threads that fate has spun” (p.6). This study looks at women’s subjective experience of this ‘knitting together’ process.

Women’s experiences were specifically focused on because nearly twice as many women live with MS, as men (Robinson, Neilson, & Clifford Rose, 2000). Even more importantly, social role obligations, and cultural values render the experience of disabling illness rather different for men and women. Women with MS seem more resistant to depression than men (Hakim et al, 2000) and make different adjustments to the disease than men. For example, they are much more likely to move from full-time to part-time work when accommodating to their illness, whereas men tend to either stay in full-time work or give up work completely (Hakim al, 2000). On the other hand, women with disabling conditions perceive themselves as more subject to discrimination (Gordon, Feldman, & Crose, 1998).

It is recognized that MS presents many barriers to achieving a quality life. Without seeking to minimize these difficulties, this report explores the more positive aspects of the lived experience of MS, focusing upon the strategies that women identify as sustaining their quality of life in chronic illness.

### **Method:**

In a qualitative study it is important to listen and value people’s own strategies and values rather than imposing culturally sanctioned, ‘outsider’ views. Because of limited previous research regarding the experience of MS, it was therefore considered most appropriate to conduct a qualitative study of the lived experience of MS, with specific reference to the strategies and experiences that enhance women’s satisfaction with life. The study was conducted following guidelines for interpretative phenomenological enquiry, as described by Smith, Osborn & Jarman (1999). This approach to phenomenological research is increasingly popular in the UK for exploring experiences of health, illness and life transitions (e.g. Golsworthy & Coyle, 1999; Smith, 1996; Smith, Flowers & Osborn, 1997).

It has much in common with American phenomenology in permitting exploration of participants' thoughts and interpretations as well as their 'raw' experiences, and in its acceptance of cultural and situational influences on accounts (Caelli, 2000).

*Participants:* Following ethical approval, twenty-seven women with relapsing-remitting or progressive forms of MS were recruited to participate in the study. The manager of a local MS Therapy Center (part of a UK-wide chain of charitable centers offering information, physiotherapy and other resources to people with MS and their carers) gave permission to place a notice in the foyer inviting women to discuss their strategies of living with MS with the named researchers. Twenty-two volunteered. The other five participants were recruited through a snowball process following initial contacts. Thirteen interviews were carried out at the MS Therapy Center, two participants were interviewed by telephone, and twelve interviews were conducted in the women's homes. The women were aged from 32 to 75 years, with a median age of 48 years. Five were 30-39, nine were 40-49, ten were 50-59, and three were more than 60 years old. All were White. They had lived with MS for 2-37 years (median length of illness 14 years). Twenty two had been diagnosed over 5 years previously. Seventeen were married or living with partners, five were divorced and living without partners, and five were single. Twenty had children, but in most cases they were adults living away from home. Four continued in regular paid part-time work and one worked full-time. They reported a wide range of MS symptoms. All reported problems with severe fatigue. Most had marked difficulties in mobility. Seven used a wheelchair.

*Procedure:* The semi-structured interview guide was given to all participants prior to interview, together with an information sheet, so that they could give informed consent and also reflect in advance on their experiences of living with MS. The interview began with a 'grand tour' question to the women to tell the interviewer about themselves in what ever way they chose. Other broad questions focussed on the effects of MS on the women's lives, the strategies that they had developed for maintaining health and managing the illness, an appraisal of their quality of life, and the experiences, roles and activities that contributed most to their satisfaction with life. Further questions were asked to probe the emerging account, and the interviewer offered reflective summaries from time to time to clarify emerging themes. Interviews usually took between one to two hours. The interviews were carried out by the first



author, a woman in mid-life, in good health, and with experience of health psychology, and counseling.

*Data analysis:* Immersion in the interview transcripts and re-listening to the tapes helped to familiarize the researchers with the women's experiences. The major aspects of the literature review were left until the later stages of the project, to assist the listening process and to avoid 'forcing data into extant categories' (Charmaz, 1999: p376). Memoing was used throughout the research process to heighten sensitivity to emergent themes. The coding of interview transcripts and the grouping of specific strategies into larger themes was carried out jointly with the second author who is an occupational therapist and counselor. The distinctive yet complementary professional backgrounds contributed to the conceptualization of themes within the data, and reduction of individual bias. Following the guidelines of Smith, Osborn & Jarman (1999), one long and rich interview transcript was first examined in detail to code the specific meaning units and to derive larger themes. A preliminary analysis of certain key themes in this interview has already been reported in Reynolds (2001). These themes were further developed, extended and hierarchically arranged as further interviews were analyzed. Particular attention was given to the themes that the interviewees had validated at the time of interview, during summarizing and reflection. An audit trail of decisions was kept to increase the transparency of the process. Whilst the themes are presented as a hierarchical list, they are no doubt cross-connected in complex ways in the respondents' accounts. A detailed report of the themes, with illustrative quotations, was given to each participant, and no adverse comment was received.

### **Results:**

Whilst almost all of the women coped with their illness symptoms through a variety of health promotion strategies, most emphasized that a quality life involved more than 'coping with MS'. The major strategies for living with MS, grouped into superordinate themes, are presented in Table 1.

**Insert Table 1 here**

## **Managing illness and limiting its impact**

Certain strategies for managing health and illness were shared by nearly all participants, namely looking after one's health, being open about difficulties, managing the impact of illness on self and lifestyle (for example, through pacing daily activities), good stress management, and resisting domination by illness.

### *Looking after one's health*

Nearly all of the women engaged in health promoting activities, including educating themselves about MS, physiotherapy, yoga, swimming, oxygen therapy, and maintaining good nutrition. Only one participant described her hope that these strategies would 'cure' her symptoms. Others conveyed the belief that by maximizing their health, strength and fitness, the symptoms of MS might be better controlled. Active self-management of MS symptoms was highly advocated. Those attending the MS Therapy Center tended to make much use of its various subsidized health promoting services and advice.

I do physio, I'm a great believer in physio. ... I do believe keep the body moving, try to get as much movement out of it as possible. There's no cure, there's no cure so, and I do think that people out of desperation jump into all sorts of things, my opinion is that you've got to try one thing and give it your all and see if it works, and if it doesn't move on to the next.

I also have major bladder and bowel control problems both being able to empty and not being able to empty. So they have a bearing on things as well... I'm trying to work out what is the best way for me for dealing with each problem and trying different regimes and trying to see what I can do. I think you've got to take advice from the people who know and then look to yourself.

Some women used a complex bundle of self-management strategies, whereas others carefully monitored the effects of individual health promotion strategies on their well-being, and were prepared to abandon those that provided few noticeable results.

### *Acknowledging difficulties*

Most of the participants described the experience of learning to be open about their difficulties, in order to move on with their lives. For example, one participant had been a full-time cook. On retiring from work on health grounds, she described recognizing that she felt isolated and alone:

...particularly the mornings on my own which I found quite difficult to start with. I think there wasn't an untidy cupboard in the house (laughter) But you find things to do.

For many, turning points in living with MS seemed to have occurred once difficulties were openly admitted, at least to themselves. However, as a later quote shows, not all women wished to reveal their difficulties to more than a few trusted friends or relatives, as they did not wish to make illness a central topic of conversation.

### *Pacing & fatigue management*

Many participants described the challenge of coping with daily activities when energy and mobility were limited. The realization that these resources would have to be managed through pacing activities and through introducing rest periods into their daily routine was rarely arrived at without some emotional struggle, as pacing strategies could be experienced as 'giving in' to the illness rather than as a positive lifestyle choice enabling valued roles and activities to be maintained.

I must admit I've found that it took a long time to accept because I've always hated not finishing a job. I've always wanted to get to the end of the job and then do whatever but now I have learnt that you might as well pace yourself because otherwise you probably won't finish the job anyway. That's how I work it.

Interviewer: So is it a way of keeping the fatigue and tiredness under control?

Yes. And also I feel in control then rather than it in control of me, to a great degree anyway. If it's impossible, I just do as much as possible sitting down.

The imagery of the 'power struggle' between the woman and the illness appeared in several participants' narratives.

### *Managing stress well*

Many of the women were not only coping with MS but other life events such as divorce, difficult teenagers, bereavement, additional health problems and so on. The coping task was regarded as considerably wider than managing the symptoms of MS alone, and applying good stress management to all life's difficulties was understood to play an important role in maintaining their satisfaction with life.

So I've been through a really horrible divorce and now I think I've got to the point where I'm comfortable with my house, my dog and my cat. Having a partner isn't the be-all and end-all of life

Nearly every participant communicated that she was more than a 'patient with MS', and that life's wider challenges had to be managed in order to gain an acceptable degree of well-being. Learning to live with stressful events was sometimes a lengthy process:

I am a survivor. Because I've got MS but I'm also 50, and I've got all sorts of other things going on in my body, things can't all be put down to MS. I'm menopausal, I lay awake half the night, I've got to worry about my bones like everybody else of my age, and so forth. I smoke like many other people....

This account seemed to place the person-hood of the woman centrally, rather than her 'patient' status, and portrays well-being as dependent upon more than dealing with the symptoms of chronic illness. This issue is also embedded within the theme of the 'fighting spirit' alluded to below.

### *Practising resistance and the fighting spirit*

Many women reported their determination to battle MS specifically and life adversities in general. The fighting spirit was seen as an important approach to dealing with the challenges of illness, maximizing function, resisting depression and restoring satisfaction with life. A young mother of three argued:

You get a relapse you have to relearn things like walking again. Or how to hold a spoon Or write with a pen.... And you have to do that fight again to basically function and function for your family. But, you can either give up and get really fed up with it. Your mind can say, 'Don't do anything' and your body says, 'That's it, I am cheesed off'. Sometimes you do that and it's OK. And then you have this choice where you could enter into a total vegetable depressed giving-up mode. Or, there is a point where I have got to start thinking you know maybe I will just practise drawing today. And maybe I will just spend five minutes washing a potato. Because otherwise what alternative do you have?... Maybe I have got a little bit of strength so maybe it is time to start living again?

The quotation is interpreted as revealing a concern not only with coping with the illness itself but with achieving some broader quality to life through regaining contact with leisure pursuits and domestic roles. It illustrates how the various themes inferred from the accounts were in fact intertwined. Many regarded their battle as being fought on several fronts simultaneously. In keeping with this perception, the narratives were often framed as a dialogue either with self or with the illness:

It {MS} is like an enemy. I think I'm going to do my damndest to make sure that you are not going to win on this one. Or I am going to get round it. It's a challenge I suppose if you think about it. Yes it is. Looking upon it as a constant challenge and saying well what does the body think about that? If you think I'm going to end up sitting in a wheelchair, no.

A major inference from these extracts is that living positively with a chronic condition such as MS is not a 'simple' matter of implementing coping strategies for illness or holding on to positive beliefs. There is often a struggle to climb out of depression and to regain mobility or purpose. A huge range of positive strategies that promote health and quality of life can be identified but they often occur in an ongoing context of battle with the negative forces of illness. There is an ongoing 'dialogue and negotiation' with MS, which seems to require effort and resourcefulness.

### **Maintaining a positive self-image**

Many of the women worked hard to resist the negative effects of MS on self and identity. In fact, in many of the opening statements to the initial broad invitation to describe the self, the woman appeared to show resistance to the ‘master status’ of illness (Charmaz, 1991), by telling the researcher first about her other subjectively more important aspects of identity:

I’m a mother of three children, the oldest is 11 and the youngest is 6 in a couple of days. I’m divorced. I’m also engaged and I have multiple sclerosis. That was diagnosed a couple of years ago.

There were four broad strategies for maintaining a positive self-image, namely engaging in activities, roles and occupations that were personally meaningful; to adapt if necessary one’s preferred occupations to suit one’s level of functioning in order to continue with them; to actively resist the disabling social definitions imposed by the wider society, and to identify one’s personal needs and future goals.

#### *Engaging in meaningful roles and occupations*

A central means of achieving a quality life was through engagement in meaningful occupations. This has been little explored in most previous research. Many participants acknowledged a period of struggle with their self-worth when MS intruded into their work-lives or studies, particularly at the point when illness led to early retirement. They described their discovery of meaningful alternative activities as a significant psychological turning-point. Whereas previously the woman tended to focus on illness-related losses, the discovery or re-immersion of meaningful roles and occupations opened up the possibility of gains. Some women sustained themselves with activities that had been a life-long passion (e.g. gardening, textile art) whilst others tried new pursuits such as horse-riding, yoga, painting, pottery, computing, counseling, and researching the family tree. These new roles and activities sometimes channelled interests and skills that characterized the women’s pre-MS life, and thereby helped to preserve some biographical continuity.

I've got loads of things to do. So life isn't at all boring. I was thinking {when I took early retirement} 'oh I can sit in the conservatory and do some cross stitch' but the chance would be a fine thing! I probably think it is better for me because if I am not kept occupied then, you know I find myself going round the bend.... For 10 years everything was black and you used to think why doesn't something good happen? ... When you get bad things {happening}, you think come on ... you get a bit teary and think I could do with a nice thing...I went to evening classes – painting. I did pottery. All the arts things.

: (Interviewer) Did that help to see you through?

Yes I think so. I went on to do a History A level as well. Because I was determined, my son was coming up to A levels and I didn't want him turning round and saying you don't know what it is like. I was always interested in history so I took an A level {a pre-university examination}

The participant describes engaging in a variety of creative and educational pursuits not only to occupy time positively, but to address another priority, namely to be a supportive role model for her son. Her actions seem motivated not only by her need to manage life with MS but her desire to maintain her role as mother and to keep channels of communication open with her son.

In some cases, participants were determined to continue in paid work because of its psychological significance (even when they had to work additional unpaid hours to keep on top of their workload). However, in most cases, meaningful occupations were leisure based, and filled the day-time void that appeared following premature retirement from work. An important source of life satisfaction was derived from embarking upon a wide range of meaningful occupations that provided structure to the day, a means of social contact, a challenging stimulus, the preservation or development of skills, praise from others, and personal fulfillment.

I suppose that the bottom line is that we'd all like to be out at work and doing the kind of working day that everybody always does, but that being the case you have to find other things that give you a sense of contributing.

I feel it's important to maintain a particular role in life and if I can do that it's fine.

Meaningful occupations (and the relationships that were developed as a result) also helped to increase quality of life by focusing attention away from illness itself:

And I love drawing and painting on my own but I really like to be able to chat with other people as well. Yes. That is the shared focus. Nothing to do with illness, but everything to do with being creative.

The significance of maintaining the mothering role featured strongly in many women's accounts. It has been noted above and will be illustrated further in another section. Some new activities were so much enjoyed that the woman came to value the illness for presenting the opportunity to try a new lifestyle:

MS was a real catalyst. When I look back and see how my life was going, I was forty five and my children were leaving home. In a job, which I did enjoy, but it was sort of seven days a week and I had time for nothing else...MS has enabled me to open up my life in so many different directions

#### *Adapting pre-illness skills/interests to current levels of physical functioning*

The women were realistic that many of their former interests and activities were difficult or impossible because of the mobility problems, fatigue or visual disturbance brought about by MS. All except one had retired from full-time work for these reasons. Such losses could profoundly challenge the woman's familiar sense of self and her biographical coherence. One way of maintaining continuity of self and identity was to find ways of adapting former skills and occupations to current functioning. Many applied the skills that they had acquired during their careers to their current activities. For example, former business skills were utilized to raise considerable sums for charity, in helping the administration of the MS Therapy Center, or in volunteering.



I'm a member of ... a committee {at the MS Therapy Center} which forms a link between the members and the trustees, so that if a member has a problem we try to resolve it. If they have a suggestion, we're their first port of call and I feel as though I'm making a contribution back to the center. I also prepare the minutes of the monthly meeting so I feel as I'm able to do that as well which is a great morale boost if you can do something. I'm co-editor of the center's tri-monthly newsletter so I seek out people's views and experiences and their funny tales and sort out informative articles as well.... It's nice to get feedback and know that it's not a waste of time.

Life satisfaction was also enhanced through adapting preferred leisure pursuits to current functional limitations . For example, a participant with relapsing-remitting MS, and increasing mobility problems, described how she had managed to continue her textile artwork by using a computerized embroidery machine to perform the techniques that her manual dexterity no longer allowed. This maintained her self-esteem and satisfaction from engaging in artwork:

I just refused to give up {embroidery} and it just escalated, and I had a .... machine from my mother, that didn't work very well, and then we bought a smaller one which wasn't particularly good, and I escalated into a computerized one which I've got now, and I think it's the fascination in the color, and it's just this sense of losing yourself, perfectly, completely, in the color, design, and just putting pieces of fabric, and something wonderful coming out of it, and that's what it's like for me.

Some women revived interests that had been mainly kept on hold during their working lives. This strategy thereby encouraged some women to interpret their illness as having some positive aspects:

I feel I'm so fortunate because I've always loved art.... But if I'd been something like a mountaineer and then took ill that would have been very hard .... I used to like playing tennis, I loved dancing, I did adult beginners ballet ... I love ballet, I love the shapes. That was great fun, actually, that was before

the illness hit. But because I've had these other things that I've loved like art, that has been great.

### *Resisting disabling social definitions*

Another common feature of the lived experience of MS was social discrimination and stigmatization. Health professionals, the general public and even friends sometimes related to the disability rather than to the person. A familiar sense of self and enhanced well-being could be gained from challenging unwelcome stereotypes and social expectations. This could be done at the community level through involvement, for example, in campaigns aimed at improving wheelchair access for all disabled people to local facilities. Others fought a more individual battle to be treated as an individual rather than as a 'patient with MS'. For example, a participant with nearly twenty years experience of having MS said:

I go to an art class on a Monday ... I was offered a social services place but I thought no I don't want to do that, I've got no qualms about being disabled but I've got qualms about being locked into a corner with, you know what I'm saying, you know I'm me with MS, you know, but a lot of these places, they are MS.... and their identity is lost, so it's not for me.

### *Identifying personal goals, aspirations and abilities*

Another recurring theme within the interviews referred to the importance of having the determination to pursue valued personal goals, and aspirations, rather than allowing life to be totally circumscribed by illness. Many argued that they would not allow illness to prevent them from reaching their valued goals in life. One participant of about 30, recently divorced, said:

When I first got diagnosed, I think I was 24 or 25, that was really difficult then because I was single then as well and it's not exactly a starting point of a conversation, and it did stop my doing a lot of things that my friends did, I couldn't go to a night-club because of the strobe lights. ...I can't walk, when strobe lights are going on, and so it did stop me doing a lot of things, but now

I don't think of what I can't do, I think of what I can do... Yes it's no good thinking of what I can't do compared with what I used to be able to do, because you'd just go mad (pause) or really depressed so I don't really dwell on it.

A young mother described her struggle to identify her needs as a person:

But I found that I needed to look back and think OK you're not just going to be a survivor. It's important that you are doing those things as a mother, it's important that you are a girlfriend, but what do you want from life? It seems selfish but I think that it is also something that is right and shouldn't be forfeited, because you are in a situation where you might be more restricted than you are normally. ... You have to fit in with other people a bit. But, also not to lose that essence of 'I', I also am a person, who needs to explore, who needs to find out and enjoy life a bit, because basically what is the point of being here if you can't enjoy life a bit as well?

Quality of life depended upon enacting at least some personal dreams and aspirations:

I have dreams. Some of them are unrealistic dreams I know but some of the dreams I have I want to do and I don't see why I shouldn't. My MS is a part of my life. I can't get rid of it. I know it's there. It knows I'm there. But I will not let it blight my life. I just will not. Sometimes, because of the nature of the illness, it does. And it does have an effect. I'm a woman and I am going to enjoy that life, even though it is a bit tough sometimes. That is basically what life is about.

The struggle and ongoing 'negotiation' with MS that has been referred to in a previous section often reappeared when participants were describing their aspirations:

Well when I have these periods of relapse or a lot of pain, I quite often have to spend a lot of time in bed. Quite often I think of things that I would really like to do, and I focus on that. I haven't ridden a horse for twenty years and while I was ill last time, I thought I would like to try that. And then you get the voice of reason which says 'no you're crazy'. 'You can hardly walk'. And

then I think blow it! I want to do that and I am in charge of my body. The MS has invaded. I have to be practical sometimes and not exhaust myself but I am not going to stop doing what I would really like to do because of it. So last week I booked up and went horse riding.

This extract appears to reveal a complex mix of strategies including practising resistance and the fighting spirit, as well as embarking on new activities. The way in which the illness is addressed almost as a shadow self is again evident. This extract also reveals how a cognitive or emotional coping strategy such as adopting a 'fighting attitude' to MS may enhance quality of life through giving the confidence to take up a satisfying leisure activity, which not only provides pleasure but a valuable sense of control over daily life.

Some women sounded a note of caution, pointing out that it was important to pursue goals that were personally meaningful, rather than striving solely to gain esteem in the eyes of others. The cultural emphasis on 'doing' and 'achieving' were seen by some to be the very values that oppress disabled people, challenging their self-worth. These participants had struggled with the dissonance that they perceived between identifying and pursuing their own goals (e.g. to be a good mother) and meeting socially defined expectations (e.g. that an intelligent woman 'should' persist in qualifying for a career).

I found that there was a point where I couldn't cope with the degree of studying plus it was set study patterns where you had to get things in by a certain time. This was very difficult when you were having problems with your arms. There was one point where I thought I am getting very stressed. I need to choose right for this moment what I am going to do, whether I am going to carry on with this or whether I am going to put my strengths into supporting the kids and being a good and fairly smiley mother for them.

### **Consciously valuing and promoting the positive aspects of life**

A strong message emerged from the accounts that a quality life was not only derived from fighting the effects of illness, maximizing health and enhancing self-esteem. In many of the participants' accounts, quality of life was associated with a wide range of further values and strategies, all focused upon actively appreciating and instigating positive life experiences on a day-to-day basis.

#### *Valuing positive moments*

Among the transcripts, there was a recurring theme of valuing the positive moments that occurred during daily life rather than taking them for granted. Participants describing this approach to enhancing quality of life had noted that illness – despite its sometimes devastating effects on the body - did not prevent positive moments from occurring, and that satisfaction with life was enhanced through consciously savoring these pleasurable experiences. Positive memories and the hope that enjoyable experiences would occur again in the future helped to maintain morale during relapses:

I remember when I first got symptoms and I feared I might have a brain tumor, and that I was going to die. Whereas whatever this {illness} does to me I feel like it has been a stay of sentence. And I have been privileged that I can see my kids grow up and be with them. At the moment I am not in hospital. So try and focus on the moments when it is OK. And I gather jewels from the week. The horse riding – if ever I have a painful time I'll focus on the feelings I had when I was riding the horse.

#### *Making constructive use of precious time and energy*

Profound fatigue is a common feature of MS. Some of the participants were adamant that they chose to increase their quality of life through judicious use of time and energy. This did not simply allow the illness to be accommodated, but provided maximum satisfaction for least energy 'cost':

Sometimes I find you do have to get rest and get quiet and gather your strength up. But, basically it is the difference between having a life as someone who is disabled, and having a life which has got some quality to it

and I think that is the most important thing. You have one chance at life. You don't want to think of yourself of someone who is going to be at the end of it, before it is. You've got the life. You've got the pain. You've got the illness. But you you've got to go for what you can while you've got it. Otherwise what is the point of being alive

Whilst the majority of the sample spoke of their need to pace the activities they enjoyed in order to manage them within the limits of their energy (as noted in a previous section) , others commented on how much pleasurable activity they were willing to squeeze into days when their physical functioning permitted:

Gardening I feel is the one thing I can do where nobody knows, they can't tell that I've got a disability, although sometimes in the summer I try and do everything in a day, for instance cutting the grass, edging it, weeding, and yes I overdo it, and um but the thing is while I feel good then I *do* overdo it because tomorrow I might not, it's not something you can say I'll do one thing today and one thing tomorrow, because tomorrow you might not feel like doing anything

Many women had explicitly arranged their lifestyle to be as satisfying as possible, deciding to cut back on mundane tasks that cost energy with little reward:

You find functional strategies, pay people to do the things that are boring, that you don't want to waste your energy on, so now I pay somebody to do my cleaning, I pay somebody to do the ironing, I pay somebody to do the heavy gardening, and OK it means that my disablement benefit, quite a lot of that goes on paying people to do things, but if I've got limited energy I'm not going to waste it on ironing shirts (pause) and I think if one were in the business of giving out advice, which one mustn't do, but should you be, that would be the piece of advice that I'd give anybody, do not waste your very limited energy on things that are boring.

There was a strong message that a quality life had to be actively managed. Without effort and deliberate choices, as well as conscious reflection on positive experiences,

illness could all too easily dominate daily experience and personal identity. However, even within the illness experience itself, some good could be discovered, as the next theme shows.

*Finding positive aspects in adversity - benefit-finding*

‘Benefit-finding’ was a strategy for enhancing well-being that was mentioned by several women, who described a variety of positive experiences that they would have missed had MS not intruded into their lives. A young mother said:

Look at the good things it {MS} has done for us. Sometimes we just go for a little walk together and sometimes {my son} talks to me and I say look you know ... he actually said to me there is a boy in his class whose Dad was ill and {my son} put his arm round him and said it's OK, my Mum gets ill. Your Dad will get a bit better. And he said the boy was crying but he cheered up a bit and then they did some cartoons together and I thought my son has learned to be caring of other people. So that is another good thing that MS has done.

*Enjoying fun and humor*

This theme overlaps with benefit-finding. Preserving a good sense of humor was seen to provide a good antidote to feelings of tragedy or self-pity that might otherwise overwhelm the person, and provided a source of quality in life. Humor also helped to improve social relationships, which had their own part to play in contributing to quality of life.

I started to think I was looking at the illness the wrong way. You've got to look at it as something other than a curse. And thinking about it, I thought since I have had MS, I have met a load of really brilliant people. People with a lot of courage and a lot of guts and humor. And also people who are very genuine. I go to the MS Center once a week and sometimes that is what psychologically keeps me going in the week, because we have such a good laugh there. We come in and {say} ‘You look blooming awful!’ And then we all laugh!

And you see having humor is good ... I think that is a huge advantage. I mean physiotherapy has given me some enormous laughs. I think you have to do that... We have a good giggle. You know the Physiotherapists are Hitler. 'Yes you can do it!' 'No I can't!' Taking the mickey and this sort of thing. It's made me a lot more outgoing .....

### *Comparing self with less fortunate others*

Some women, seemed to gain appreciation of their life circumstances by comparing their own fortunes with others who were more disadvantaged.

If I get a particularly bad day where every now and then I have a good cry, and I get the 'Why me?' syndrome, the it goes away and I pull myself together, and then when that happens, I just try and move on and tell myself that there are a lot of people much worse off than me, and there are a lot of children that are really ill, they haven't had as many years as I've had.

### **Maintaining mutual relationships**

Social relationships were regarded by almost everyone as central to the experience of having a quality life, both in terms of receiving love, support and confirmation of self, and also in terms of the satisfaction of caring for others. For many, it had taken time to accept social support during illness, but it was now considered to make a great difference to quality of life. Friends were also valued, not only for their support, but for the fun and humor that they provided. Most of the sample referred to their need to *give* others support as well as to receive it, thereby continuing to maintain *mutual* relationships. The women who were mothers all spoke of taking pride in continuing to offer emotional care, guidance and support to their children, even if their physical condition did not allow much practical caring. Indeed, they often described prioritizing their families' needs above their own. Continuing involvement in caring relationships seemed to provide a vital experience of continuity, self-worth and fulfillment. Illness was experienced as particularly devastating if it intruded into their capacity to be a 'good' mother:



I have always been fairly resourceful but I think that I have become more aware of the importance of building up things that will give joy as an individual and as a family. I really, really appreciate the days when it's good, the days when there is a bit of sunshine and the days when ... there was one day I forced myself to walk to the park with the boys and we played some football and that was so special. On the way back, my boys said this is a memory day. And I thought yes. And that has become like a motto.

Another described similar values:

I think the important thing is that I feel able still to be a mother, a wife and also part of the outside world as well. I feel as though I can still contribute which is very important I think.

One participant described how she took pride in being able to care for a teenage daughter who had been ill for a year:

She's a lot better now than she was. But that year was not only difficult for her but it was very difficult for me as well. We've come through that. And I don't know whether it sounds bad or what but it has helped me a great deal knowing that I was able to do it. I was able to do what an ordinary mum would have done. Although I hated my daughter being ill I was so pleased that I was able to support her and look after her. Although I found it exhausting and very difficult, I was able to do it.

Others emphasized how good friends maintained their status as a person rather than a 'patient':

Good friends ... actually see me before the wheelchair... I find that some people see the wheelchair before me.

Helping others in a volunteer capacity also provided a source of self-esteem and pride, and sometimes helped to enhance quality of life through structuring weekly routines.

One woman had started to help children with reading problems at a local primary school:

I suppose that the bottom line is that we'd all like to be out at work and doing the kind of working day that everybody always does, but that being the case um you have to find other things that give you a sense of contributing, that sounds very (pause) pious um, 'contributing' in some way ... one of the things that you discover about these very young children is that if they're failing at reading they're pretty well failing at everything, that's one of the sad things....so if they can spend half an hour with somebody, it doesn't matter how small the achievement is, they are hearing an adult say 'that's brilliant, that's terrific, didn't know you could do that' you then give them a sense that they're not failing ... it gives me a sense of achievement because (pause) it goes both ways, you get the sense of achievement because a little kiddy who's failing is beginning to achieve a bit.

### **Clarifying values and meanings**

For many participants, serious illness seems to have encouraged deep reflection on the meaning of life, and clarification (and sometimes revision) of their philosophical and religious values. Others had considered the meaning of illness in personal and general terms, in order to arrive at a personally acceptable reason for having MS. For example, in response to a question in the last part of the interview about what helped her take a positive approach to life, a participant replied:

I suppose yes, accepting it. But, it's sort of well 'I've got MS – can't do anything about it'. Some people get arthritis. And people do say 'why me?' I've always thought 'well why not you?' We're not special. It just happens that way.

For some, the illness experience had also thrown religious beliefs into sharp focus:

But I think one of the things in my embroideries is wanting to stay close to God too and particularly when I do the religious ones and then I can feel close and I put on my Gregorian chants ..wonderful music. ... Sometimes I chat

about things {with my daughter} and we talk about my death and whatever and that Jesus will take care of her and she says yes but not yet. Oh no, not yet! Because I just feel I don't deserve the things that I've been given but I'm so grateful for them.

The above quotation not only reveals the value placed upon self-expression through creative activity, but illustrates the benefit-finding that many of the women – particularly those with religious beliefs – include in their narratives. This respondent in talking of 'not deserving things' is referring to the support provided by her family and her artistic talents, not MS. The quotation below also reveals the ways in which seeking meaning, valuing precious moments and benefit-finding are intertwined:

And you know, in a way it {illness} has made us think of things in a deeper way because we really, really value the moments when we can just relax, kick off, have a laugh. It's made life in a way deeper.

### **Living with MS: the complexity of women's strategies and their change over time**

This paper has focused on women's strategies for enhancing the quality of a life lived in the context of a progressive illness. Whilst participants found it meaningful to discuss their positive strategies, it is important to acknowledge that they also faced many difficulties and set-backs. The narratives were not simply 'heroic tales'. Pain, deteriorating function, uncertainty, social discrimination, problems of access to public buildings, lack of suitable transport, financial hardships, difficulties in gaining financial assistance for life-enhancing adaptations within the home environment, regularly impeded coping and satisfaction with life. Some women became tearful when recounting these losses. Illustrating how external factors can impede personal strategies of coping with an altered lifestyle, the following participant described an absorbing new leisure pursuit discovered after her early retirement from work which now gave her much satisfaction. Nevertheless, as a wheelchair user, she was finding that transport difficulties were making it difficult to pursue the more advanced research into her family tree that she wished to accomplish:

You find things to do (after retiring). Then I started using the computer more because I decided to look into the family tree. So I kept quite busy doing that, it's surprising how the time can soon go. And that's really the main thing that I do now is work on that. And as I say that keeps me quite busy. But it's just getting to the stage now where I need to go to places which is not so easy.

Another wheelchair user described difficulties in socializing because of poor environmental access:

Well, I go to the pictures sometimes and I go to the pub. I've got a few friends around and I go out with them. Not a great deal, I mean the fact that I'm using a wheelchair and things does limit the amount of things that I can do, to be honest with you, because most of my friends' houses are inaccessible, and even if I could get in the door, I couldn't use their {toilet}, and MS affects your bladder so much, you know, you'd have to go on a drought for ages, before you go out, so you know that you're not going to need to pee.

These difficulties and barriers to quality of life have not been focused on in this paper, but they undoubtedly complicated participants' attempts to maximize well-being. The co-existence of positive and negative experiences seems to indicate the proactive, ongoing 'negotiation' with the MS illness experience that is required in order to achieve an acceptable quality of life.

As a final point, many women argued that their strategies for achieving well-being and satisfaction with their lives had changed over time. An initial period of variable length following the appearance of symptoms and diagnosis of MS tended to be marked by emotional turmoil and a strong sense of dislocation. In many cases, several years elapsed before participants had successfully constructed positive ways of interpreting the illness experience, clarified goals, experimented with different lifestyles, and accepted support. Additionally, the women's ways of managing life with MS continued to be subject to change in order to accommodate both day-to-day and longer-term fluctuations in physical functioning, self-image, values and life circumstances. Many participants argued strongly that individuals learn to live with

MS in a variety of different ways, and that coping is never static. One 50 year old woman who had lived with MS for over 25 years argued:

Nobody goes through the emotions in the same order and sometimes you have to allow yourself to go back and go through one or more of the emotions again and again, however long it takes for you to deal with it yourself... And to allow yourself the right to do that. The right to be unhappy, the right to feel all the different things. You need to learn about yourself. To listen to your body and to find the best ways for you to deal with the different situations because not everybody is the same. Situations are different and the way people emotionally as well as physically deal with different things. Keep active. It's essential, keep active mentally and physically as much as you're able to do.

Another woman in summarizing her philosophy for living with MS indicated her belief that coping is a far from a static achievement. She also described the personal importance of relationships, her strategy of valuing precious moments and her attempt to reframe her relationship with MS (all themes referred to in previous sections):

I think friends, communication, sticking jewels in your life, and remembering that you are here to enjoy life {are central}. It's not divine retribution. It's an illness. That's all it is. Don't let it dominate. Don't say 'I've got MS, poor me'. Bugger that for a life! ...And you have to develop different strategies I think. Basically you're a person who is evolving and changing. All people are. And what might be a good strategy for you one day, might be totally irrelevant and useless another.

Taken together, the various themes appear to illustrate a central challenge of MS, which is how to adapt to the illness whilst preserving an acceptable, satisfying lifestyle. At the level of self-image, some strategies appeared to preserve continuity of self (e.g. preserving involvement in valued occupations, using pre-illness skills, clarifying personal values) whilst others embraced change and positive growth (e.g. taking on new occupations, revising priorities).

## **Discussion**

The thematic analysis of a rich body of interview data revealed the complex, intertwined attitudes and strategies that women with MS devise to promote their well-being and satisfaction with life. Although most participants believed that the illness itself required a range of practical, cognitive and emotional coping strategies, achieving a quality life in the context of illness required a much broader approach. Active participation in a variety of valued pursuits and relationships, and maintaining a balance between identity preservation and reconstruction appeared central to achieving a quality life.

The qualitative research methodology was valuable for uncovering a wide variety of strategies that promote well-being. It seems that questionnaire rating scales may misrepresent the flexibility and evolution of coping strategies through providing static 'snap-shots'. The inter-linking of values and strategies are also difficult to monitor through quantitative assessment (for example, how trying new valued activities or adopting a policy of valuing precious moments may both reflect and encourage benefit-finding). The problems inherent in quantitative measurements of coping have been noted recently in other qualitative research into living with illness (e.g. Thompson, Kent & Smith, 2002).

Furthermore, positive experiences were inter-woven with the distressing aspects of illness in the women's accounts. Distress was often associated with discomforting and uncontrollable changes in bodily functioning and lifestyle, social discrimination and socio-environmental barriers to participating in life as an equal adult. Positive growth was often associated with clarifying priorities, experiencing agency, making a contribution to others and reaching valued goals. External factors, such as social discrimination and inaccessible environments, could limit quality of life almost regardless of individual strategies. The complex co-existence of acceptable and unacceptable domains of life experience indicates that building a good quality life requires more than a repertoire of problem-focused 'coping strategies' specifically for illness, and suggests that psychological stress-coping models (e.g. Pakenham, 1999) require supplementation. That people with a chronic condition may experience a normal biography co-existing with a disrupted biography has been noted in other recent research (Sanders, Donovan & Dieppe, 2002).

Some of the cognitive, emotional and practical coping strategies for living with MS identified in the current study have been documented in previous research. Examples include health promotion and clarifying spiritual values (Stuifbergen & Rogers, 1997), benefit-finding (Mohr et al, 1999), and supporting others as well as receiving support (Schwartz & Sendor, 1999). 'Valuing positive moments' seems to be a strategy similar to that described by Charmaz (1991) when she described people with chronic illness as 'living in the intense present' although participants in this study conveyed a reflective as well as experiential dimension to this strategy. Similar experiences as noted in this study have been reported in other analyses of qualitative accounts of living with serious illness, including benefit-finding, appreciating authentic mutual relationships, drawing on faith, taking on new life plans, adapting professional skills to new tasks, and engaging in public education campaigns about illness or disability (e.g. Breaden, 1997; Thibodeau & MacRae, 1997). These overlapping themes indicate perhaps that there are certain common challenges in building a quality life in the context of chronic illness.

The study indicates that positive attitudes and cognitive or emotional coping strategies not only enhance well-being not only in their own right (e.g. positive beliefs may confer resistance to depression) but through their translation into the activities of day-to-day life. In particular, the participants perceived that their quality of life derived from maintaining valued roles and occupations, and retaining familiar elements of self. The discovery of meaningful occupations compatible with personal skills and interests seemed to provide turning points in many women's capacity to live positively with MS. A need for alternative occupations was particularly pressing once illness had led to early retirement from work. Most of the women in the current study had been diagnosed with MS many years previously and in line with previous estimates (Jackson & Quaal, 1991), only one was employed full-time. The narratives conveyed clearly how a quality life depends upon filling the occupational void that opens up following retirement from work. Unless this void is satisfactorily filled, boredom, isolation, depression and biographical disruption are likely to ensue.

The women in this study found a range of ways to use previous work-based skills and interests, in new roles such as volunteering. Their accounts also suggested that previously dormant interests (for example in the creative arts) were sometimes

revived when paid work no longer dominated daily routines. Such lifestyle change could be very fulfilling leading to 'benefit-finding', a strategy noted by researchers such as Mohr et al (1999). The interviews confirmed certain aspects of the lived experience of illness that a number of individuals with MS have previously discussed in autobiography, in particular, that positive turning points in the process of identity reconstruction during MS are associated with finding fresh purpose and meaning in life, and new roles that require the application of self-defining, pre-illness skills (Monks & Frankenberg, 1995).

Previous studies have documented that MS is associated with reductions in the variety of leisure and domestic activities (e.g. Eklund & MacDonald 1991; Finlayson et al 1998; Lundmark & Branholm 1996) but there is little information about ways in which people preserve or extend their activities. This study uncovered a wide range of leisure and voluntary activities. Most activities were quite sedentary, as would be expected given the women's mobility and fatigue problems, but some physical activities were also noted including yoga, and horse-riding. In general, valued activities provided stimulation, a sense of identity, self-esteem, and social contacts. Activities appeared to have been taken up in response to opportunities (eg for volunteer workers at the MS Therapy Center), family encouragement, as well as personal decisions, including a need to 'prove' oneself to be in control of one's life. Whilst the most seriously disabled women perceived fewer opportunities for exercising choice over activities, mobility restrictions were not their only barrier. Difficulties in accessing suitable transport, limited care assistance and financial hardship also restricted their occupational options. Meaningful goals and projects have been described as contributing to well-being during health, aging and illness by a range of other authors (eg Becker, 1997; Kaufman, 1986; Wilcock, 1993). For genuine rehabilitation to occur, disability benefits need to be set at levels that enable greater participation in personally meaningful activities within the community.

It is important to note that the positive strategies and activities that give meaning to life during chronic illness are the same as those giving meaning during health. Self-actualization has been noted as a central human need in the person-centered tradition (e.g. by Maslow and Lowry, 1998) and previous studies of people with MS have confirmed the presence of this motive, as discussed in the literature review. Being an



active member of a social circle, helping others, and exercising choice over lifestyle would all seem to be general human preferences, at least in Western cultures which value autonomy (Becker, 1997).

Care inevitably has to be exercised in generalizing from the study, as the sample is probably not representative of the population of women with MS living in the community. It is difficult to be certain of participants' motives for volunteering, but they may have been particularly confident about discussing their strategies of living with MS. The sample was mostly well educated, and most of the women lived with a partner whom they described as providing emotional and financial support. The majority had regular contact with a Multiple Sclerosis Therapy Center. Such a resource may have provided a high level of social and practical support, contributing to the coping process. Also, people attending the Center may come from a section of the MS population that has already achieved considerable acceptance regarding illness. Those struggling to acknowledge the reality of that illness might be reluctant to attend a designated center. Furthermore, most participants had been diagnosed for more than five years. Having had some time to grieve and adapt, they may have been more readily able to evaluate their quality of life in positive terms than people with a recent diagnosis, and to be satisfied with the balance they had achieved between managing illness and leading a full life, and between preserving some aspects of the self and embracing change. Nevertheless, the positive accounts of such an 'experienced' sample may provide hope to others who have received a recent diagnosis.

Caution is also needed in taking the participants' accounts at face value. However, interpretative phenomenological research adopts the assumption that people provide others with a genuine portal into their experiences, beliefs and enduring strategies, through their verbal accounts. In contrast to some discourse analytic research, phenomenological research resists the idea that narratives are performed in the moment of the interview to generate a certain managed effect on the interviewer. Nevertheless, the influence of the social context on interview content must inevitably be acknowledged. In particular, it remains unknown how far the values of the MS Therapy Center might inform participants' strategies of 'fighting' mastery by the disease, thinking positively and so on. It has been argued that the MS community

tends to encourage positive beliefs about illness and the fighting spirit (Robinson 1990). It is possible that those attending a MS Therapy Center might have been particularly socialized into this culture. Also the Center provided health promotion, social activities, and many opportunities for volunteering, thereby helping participants to achieve an active, varied lifestyle. On the other hand, the women joining the sample from other sources also provided similar themes in their accounts, showing that a range of other community organizations and resources could be useful for rebuilding a quality life (e.g. the Women's Institute, the Embroiderers' Guild).

The effects on participants of being interviewed by an apparently healthy person is unknown. It seems possible that interviewees may have been more upbeat about their quality of life than they would have been if talking with a person who shares their illness, as a defensive or self-presentational strategy (Radley, 1993). On the other hand, similar emphasis on the importance of meaningful roles such as mothering and volunteering, and the possibility of personal growth, has been made in several autobiographies of people with MS, written primarily for audiences that share the same illness (Brown, 1984; Burnfield, 1985; Forsythe, 1988; Webster, 1989). The claim by many participants that there is no alternative to coping and making the best use of skills need not be an artefact of self-presentation or a self-delusion (Taylor & Brown, 1988). The human capacity to adjust, exercise choice, find meaning in adversity and so on, regularly seems to flourish in difficult life circumstances (as noted by Becker, 1997; McAdams, Josselson, et al, 2001; Tedeschi & Calhoun, 1995). Nevertheless, any simplistic inference that MS is a readily manageable experience needs to be strongly resisted as does a belief that people with MS simply need determination to gain a satisfactory quality of life. There are strong cultural pressures on chronically ill people to be stoical and accepting, leading to judgements that they are 'failing' if emotionally distressed by their condition (Webster, 1989). It is important for researchers and health professionals to resist these influences. It is also important to recognize the effects of the research question on the perspective gained. Previous research, by asking how MS has changed or affected participants (Mohr et al, 1999) or how participants manage self-care (e.g. McLaughlin & Zeeberg, 1993), have illuminated these particular aspects of the illness experience, but have not revealed much about the wider issues connected with achieving satisfaction with life. This project, by asking women about the experiences that provide satisfaction when

living in the context of MS, has uncovered wider needs, aspirations and many stories of triumph over adversity. It is almost certain that had the researchers asked participants to focus on their difficulties in living with MS, a less optimistic picture would have emerged.

Webster (1989, p135), with personal experience of MS, discussed the challenge of living 'with integrity'. The participants in this study have contributed their own insights about how they are meeting this challenge. In so doing, the narratives seem to have illuminated the process of biographical reconstruction during illness, seen by Corbin & Strauss (1987: p266) as 'discovering what aspects of self remain and can be carried forward to provide biographical continuity, and...what new aspects can be added...to give new meaning to biography'.

In conclusion, participants portrayed the experience of living with MS as a complex struggle, and revealed a wide range of strategies that gave meaning and quality to a life lived in the context of illness. Whilst strategies for managing the illness were important to them, they also emphasized that successful adaptation to MS requires more than the achievement of functional independence. Professionals working in health and social care may learn from these accounts. Their central message concurs with Radomski's argument that, 'there is more to life than putting on your pants' (Radomski, 1995, p487). Rehabilitation professionals may infer that they need to do more to help people with MS discover and maintain active roles, and engage in feasible, personally meaningful leisure and social pursuits that draw upon their existing skills and interests. Such strategies appear helpful for managing the impact of MS, enabling a balance to be established between preserving certain aspects of identity, and engaging in personal growth.

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**Table 1: Strategies for achieving a quality life with MS - the most frequently occurring themes and superordinate themes within the interview data.**

*Managing illness and limiting its impact*

- Looking after one's health
- Acknowledging difficulties
- Pacing & fatigue management
- Managing stress well
- Practising resistance and the fighting spirit

*Maintaining a positive self-image*

- Engaging in meaningful occupations and roles
- Adapting pre-illness skills/interests to current levels of physical functioning
- Resisting disabling social definitions
- Focusing on personal needs, aspirations and abilities

*Consciously valuing and promoting the positive aspects of life*

- Valuing positive moments
- Making constructive use of precious time and energy
- Finding positive aspects in adversity (benefit-finding)
- Enjoying fun and humor
- Comparing self with less fortunate others

*Clarifying values and meanings*

- Reflecting on religious/ philosophical beliefs
- Revising and articulating personal values
- Making personal sense of illness

*Maintaining mutual relationships*

- Building up social support
- Appreciating the company of friends
- Prioritizing one's family's needs
- Helping others