

# 12 Women's Narratives of Living with MS in the Family Context: Reconciling Complex Experiences, Integrating Complex Identities

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## **Abstract**

This study explored women's strategies for living with multiple sclerosis and whether/how they maintained satisfaction with life amidst loss of physical function. The family context emerged as a complex influence on participants' process of managing illness and identity. Four narratives are examined, provided by women in mid-life, with husbands and teenage/adult children. Participants described many positive strategies for resisting domination by illness, whilst also revealing numerous struggles, particularly in relation to being a mother and wife who has MS. The narratives could not be easily classified as they contained many contrasts and tensions. For example, the women described receiving much care from family members, but also clearly provided much care in return; they saw themselves as having special needs but also great strengths; they often presented themselves as strong, but at certain points admitted being overwhelmed by their situations; some oscillated between seeing their illness, or their families, as the most stressful aspect of life. The stress of illness varied to some extent according to the responses of family members. Participants accepted that MS inevitably affected everyone in the family system, but they simultaneously worked to protect other family members and to minimise its intrusiveness. Coping with illness did not only reflect individually chosen strategies. The women drew upon stories handed down from parents and other family members about their ways of confronting adversity. The numerous tensions within the women's stories of coping with MS show that illness is socially embedded and illuminate the complexity of lives and social identity.

## **Introduction**

This study sought to explore women's strategies for living with multiple sclerosis (MS) examining whether and how they maintained satisfaction with life amidst loss of physical function, such as mobility, continence, vision and energy levels.

There are many perspectives available for understanding the experience of a chronic illness such as MS. The transactional perspective on coping has been widely applied to understand the stress of serious illness. It portrays coping strategies as largely individually chosen, in relation to cognitive appraisals, emotional needs, and personality rather than shaped by what is possible within the social context (Lazarus and Folkman, 1984). This perspective also acknowledges that social support can offer an important resource for coping, but care and support tend to be represented as a one-way process from able-bodied to disabled or ill family members. The possibility that the disabled family member actively cares for others and has other concerns and roles apart from coping with being 'ill' or being a 'patient' is rarely explored.

Narrative approaches to understanding the illness experience hold out a promise of better capturing the dynamic nature of the illness experience, and the personal and cultural resources that people draw upon to make sense of their situation. Crossley (2000), for example, notes that people with HIV tell a range of distinctive stories about their illness. Some tell tragic stories in which they focus on the irremediable losses that illness has brought into their lives. Others normalise their life story, denying that illness has made any major difference to their roles, aspirations or likely future. A third group tell more triumphant stories in which some good (such as spiritual growth) has come out of adversity. The third pattern has been described as a 'redemption' narrative by McAdams and Bowman (2001). These authors argue that there are strong cultural forces encouraging people to interpret negative situations as essentially remediable - albeit with varying degrees of 'risk, effort, costs and benefits' (p.17). Robinson (1990) noted a large proportion of positive ('progressive') illness narratives written by people with MS about their condition. Relatively few accounts were focused on the loss of valued goals (regressive narratives).

Whilst rich in documenting the distinct and complex ways in which people story the illness experience, such approaches have tended to neglect the family context of the story-maker, and whether it constrains or enhances the types of story that can be told about health and illness. This paper focuses on women's narratives of living with MS, specifically examining how participants represent the family context as affecting their ways of living with illness. In what ways do women portray their family contexts as helping them, or hindering them, in devising an acceptable quality of life with MS? Can their narratives be classified as progressive, regressive or normalising?

## **Method**

Following ethical approval, an invitation was placed at a local MS Therapy Centre for women to talk to the researcher about their strategies for living with MS.

The sample of four women focused on here has been selected from a larger sample of participants who recounted their strategies of living with MS. All four were married with children in their teens or early twenties living at home. All were very experienced in living with MS, having been diagnosed more than four years previously (see Table 1).

The narrative interview began with a 'grand tour' question inviting the women to tell their stories about themselves and their illness in their own way. More specific questions were asked, as needed, about the strategies, roles and activities that helped participants to gain an acceptable quality of life. Interviews usually took between one to two hours.

The extensive interview transcripts were searched for each section in which the participants referred to any aspect of their family context, and its effects on their coping, adaptation, well-being or identity. An attempt was made to classify certain common thematic issues and the types of story being told.

## **Findings**

During the interviews, the participants described a number of positive, life-affirming strategies that they had discovered over time for living with MS, including appreciating positive moments each day, and engaging in fulfilling occupations. However, their narratives revealed certain struggles, arising particularly in the context of managing chronic illness in a family context. The narratives included many references to their family roles (eg. as wife and mother). These roles appeared to provide a valued continuity in their identities, but they could also act to constrain the participants' preferred styles and strategies of living with MS. Family difficulties (unrelated to MS) also made the illness experience more problematic at least from time to time. Families were portrayed as providing certain strengths and resources to the participants, but also as setting up certain dilemmas and tensions around the management of illness.

Participants represented life with illness in a family context as a complex challenge with both helpful and disruptive forces finding expression within the same narratives. The participants were not only engaged in coping with their illness in a personal sense, but were actively managing (and trying to optimise) a family context in which all activities, relationships and behaviour were

intimately affected by the presence of MS. As a result, the women all seemed to regard their identities as preserved in some aspects and threatened in others.

Their stories revealed numerous tensions and apparent conflicts. These are summarised in Table 2, and are illustrated with some quoted extracts from the interviews.

**Table 1: Summary of Participants**

<b>Name (Fictitious)</b>	<b>Age</b>	<b>Time Since Diagnosis</b>	<b>Marital Status</b>	<b>Work Status</b>	<b>Children</b>	<b>Mobility</b>
Roberta	50	17 years	Married	Gave up work with onset of MS to look after young children	4 (youngest 17)	Wheelchair user, urostomy
Christine	54	4 years+	Married	Retired from nursing	2 (26, 24)	Wheelchair user
Jean	48	17 years	Married	Retired from police. Antiques business (part-time)	2 (aged 20 and 23)	Good mobility
Sandra	50	25 years	Married	Early retirement from university administration	2 (22 and 19)	Walks with a stick

**Table 2: Some Conflicts in Managing MS in the Family Context**

- Being proud to be a 'good' wife and mother - feeling inadequate as a wife and mother
- Prioritising personal well-being - prioritising family well-being
- Living in both a 'normal' and 'abnormal' family context
- Receiving care - providing care
- Coping with the illness - coping with family reactions to illness

### **Being Proud to be a 'Good' Wife and Mother - Feeling Inadequate as a Wife and Mother**

A dominant theme within the interviews related to the struggle of being an adequate mother and wife. Family roles were exceedingly important to each participant's identity, as may be inferred from their priority position within the narratives at the outset of the interview. Each participant answered the initial 'grand tour' question by describing her family relationships and commitments as well as her illness:

Sandra: I'm 50 years old and I've had MS for over 25 years now. I'm married with two children, one is 22 and one is 19. James is at university. He's doing economics and management and Anna is at college doing business and retail management. ... I live here with my family but both of our families live up north. So when we go visiting we flit around between different relations here, there and everywhere. I'm one of four daughters, my twin unfortunately passed away three years ago, but we're a very, very close family. We support one another. We're forever on the phone.

Although Sandra mentions her MS in the opening sentence of the interview, she spends far longer talking about her family before pausing. Perhaps the opening statement is intended to remind the interviewer that she is not simply talking to a 'patient' or person totally defined by an illness label, but is relating to a person, with a long history, who matters to the people in her social circle and who does 'normal' things such as visiting and phoning her relatives. There is emphasis that support is given *and* received. Jean provides another example, referring to her family as well as her diagnosis in the opening statement.

Jean: My name is Jean. I'm 48. I was first diagnosed with MS in January of ... let me get this right ... January '85, but it was after a year of quite devastating illness. My children were 2 and 5. And I went back to work. I went back to work in the

September. I must admit I wasn't terribly happy about going back to work but with two children, what can you do?

These opening statements appear to represent the roles of wife, mother, daughter and sister as central to identity, perhaps more so than having MS. They also provide clues to later themes, such as the pressure to look after family even at the expense of one's own well-being. However, threaded through all accounts was concern about how the illness threatened in some ways to undermine their roles as mothers, and wives.

Jean: I think they {the children} are supportive. Yes. They are supportive. I have days when I get a bit fed up about things. And they have days when they get a bit fed up with things ... And I feel that - quite rightly I feel that - {my daughter} thinks that I'm a bit of an encumbrance now because I used to do so much flitting about here, there and everywhere and going swimming. Because I was a swimming instructor, I can't even swim now because I can't manage. So my daughter is very kind but because I don't have plaster of Paris on my legs she thinks I should be able to do what I want to do.

For Jean, her children are both supportive whilst simultaneously regarding her as 'a bit of an encumbrance'.

### **Prioritising Personal Well-Being - Prioritising Family Well-Being**

Whilst the participants saw their illness as demanding attention (through requiring time for rest, physiotherapy, stress management and so on) so too they also tried to cater for the needs of family members:

Sandra: I had to stop work about 10 years ago because of the MS, I couldn't guarantee how I was going to be ... not just from one day to the other but from one part of the day to another. So it just wasn't practical, it wasn't fair to the employer and it wasn't fair to me or the family because when I came home I couldn't guarantee I could prepare them a meal. The children were only little then and it wasn't fair to have to give that up {mothering}. It doesn't do an awful lot for your morale that bit.

Roberta explained how MS was only one of the problems that she was coping with:

Roberta: I reckon I could cope with MS if that's all I had to cope with. I'm not saying it would be easy, I'm not saying it would be a piece of cake, but I'm saying I think I could do it, and put some quality into my life. Like most mums I need to put myself first but I can't.

There was much more to coping with illness than addressing personal health problems. As with mothers in many other situations, family needs were sometimes put first.

### **Living in Both a 'Normal' and 'Abnormal' Family Context**

Within the narratives, participants made it very clear right from the outset that they participated in a 'normal' life, yet their illness also simultaneously created an abnormal situation:

Christine: But I'm now finding that my mobility is so poor that when we went away at the weekend George tried to lift me in the caravan which is quite narrow at the door and we both fell down. We'd both been drinking, so we laid on the ground laughing but then eventually we got in the caravan. We really do enjoy caravanning.

Often potentially embarrassing incidents such as falling down or incontinence were treated with humour in the narratives, woven into the fabric of stories about loving, accepting relationships. The women emphasised how they made efforts to maintain the 'normality' of family activities, for example, trying as far as possible to minimise the intrusiveness of their illness, and believing that it was 'right' to relieve family members from caring responsibilities from time to time:

Christine: We enjoy holidays. ... I have a sleep in the afternoon and George goes off and plays golf. Sometimes he plays golf all day, which I don't blame him. But then it's good because he plays golf with this friend of ours whose wife is blind, she has a rest and he plays golf with this friend of ours so they have a whale of a time so that's one thing that channels them. This is one thing that Sally and I feel, that we need to step back, they must have their own space ... So he does a lot of things but I'm quite happy (pause) no I'm not really happy, I get very frustrated that I can't do what I want to do, but I'm better sitting on my own. I didn't used to be an 'on my own' person but I'm quite happy just sitting on my own reading because I quite like reading. I didn't used to read, I couldn't be bothered to read because I hadn't got time. But now is the time for me to start reading. So it's right, I make do with things now that I couldn't do before.

This is an intriguing extract in which Christine claims at the same time that she is happy to put her own needs last, and not happy to do so. She has apparently decided to accept a more sedentary way of passing her leisure time in order to allow her husband the time to pursue his own interests. It seems that she is mindful of maintaining an equitable balance of give and take in the relationship.



### **Receiving Care - Providing Care**

The extract above acknowledges that participants were concerned to juggle their own needs for care and support with the needs of their families. There were many other places in the interviews which emphasised that care was far from a one-way process from able-bodied family members to the disabled person. All four women described their own families (husbands and at least some of their children) as supportive, and providing them with much help and care.

Sandra: I'm very lucky because my family are very supportive. If I'm having a bad day ... Susan when she's home from college will sort dinner out. John always does the shopping and that sort of thing.

Whilst the women described their families as providing them with much care and support, they also recounted many different instances of being the primary caretakers of their families, even at great costs to their own health.

Sandra: {My daughter has been} very ill. The doctors couldn't say what it was but it was glandular fever related and she was ill for 18 months ... I drove her into school and brought her home every day and many times she wasn't well enough to go at all. And sometimes I'd drive her there and she wasn't well enough to get out of the car so I'd come all the way back again with her. But I felt it was important she wanted to make the effort and to encourage her to do that. ... 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, but I was able to do it.

Once again, the ideal of being a 'normal mum' - even at the expense of the woman's own health - is embedded in the account.

### **Coping with the Illness - Coping with Family Reactions to Illness**

Each participant recounted many ways in which she was dealing positively with the limitations imposed by illness, eg. by carefully pacing activities to manage fatigue, and by modifying favoured activities (such as gardening) to suit current levels of physical functioning. However, the narratives suggested that there was much more to 'coping' than addressing illness symptoms. Whilst family members could be supportive, they could also increase the stress of

illness. One participant's account particularly highlighted the difficult task of coping with teenage children's emotional reactions to the illness:

Roberta: ... And the younger one, when his mates came round, I had to go in another room, {he was} embarrassed. And then when I was allowed to meet his mates, I wasn't allowed to walk, because my walking is not nice. I've realised that I'm more acceptable in the {wheel}chair than walking because I look as though I'm just sitting down. When I walk you see that this body really doesn't work, and it's in your face (sighs). It's difficult, it's difficult for my husband (whispers ...) ... I would have liked the younger one to have been a bit older, and got this shit out of the way.

Roberta faced hurtful behaviour from her son:

Roberta: I just want to get the house running smoothly, and tell the kids to grow up, please grow up. {My 17 year old} keeps turning off the electric chair. If there's going to be a confrontation I think 'I don't need it, turn around and go out of here'. He turns it off, blocks the doorway. I must say that I'm very disappointed that a son of mine is taking advantage of a disabled woman, I thought I did a better job than that.

Yet elsewhere, she revealed that she understood her son's fears and anger:

Roberta: It turned out that he was frightened that I was going to die, well I nearly did die. So I confronted him with that when I was well enough ... I think that the children had trouble seeing it {the reasons for their behaviour}.

### **Are Coping Strategies a Personal Choice? Or Influenced by Family Traditions?**

Lastly the analysis focused upon whether the accounts portrayed coping strategies as a personal choice or as influenced by family traditions. All four women referred to the importance of having a positive, 'can do' attitude to living with MS. Yet these strategies did not seem to be entirely 'self-invented'. It appeared that family stories of confronting adversity had been handed-down by parents, siblings and others. These provided role models for coping with MS.

Sandra: You have to look to see 'the situation is thus, how do I deal with it?' And that's the way that I've found it's possible to get through. That's how I do it. But my parents ... my father had chronic bronchial asthma for many, many years and you just had to watch his dogma, his determination, he was going to deal with it and you pick this up and you carry on. My mother she was 85 just before Christmas and she's in a nursing home since we lost dad, she lost one of her legs

... But her determination, her ability to remain cheerful and not accepting but *dealing* with it is remarkable, it really is ... I think you learn, you notice, you're not taught it, but I think you pick it up as you go along, don't you.

Roberta : My mum, she was a fighter, and life dished her out a load of shit, and she kept coming back, ... so I suppose that it's there ... She had a lot of miscarriages before she conceived, she had to stay in hospital a long time before she had us. Um I'm a twin but I was a triplet , one was stillborn, and my other brother is now dead, he had a motorbike accident and was brain damaged, and then he died of cancer. There's a lot she's dealt with. I've got another brother who's schizo. Got schizophrenia. So she's dealt with a lot. She started Headway locally after my brother died, because she found when she looked after him ... she found that there was no help. ... Strength, yes. I think it goes through the generations to be honest with you, because not just my mum but my mum's mum (pause) and her sisters and my aunts ... they've been fighters all along the way.

Narrative researchers have commented that stories are drawn from cultural resources (eg. McAdams and Bowman, 2001). The ways in which stories of coping may be influenced by family 'scripts' deserves further attention.

## Discussion

The narratives as a whole did not situate illness 'centre stage'. Even though the interviews invited reflections upon the general experience of living with illness, the participants brought their roles as wife, mother, daughter and so on, to the forefront of the narrative. Perhaps this was because family roles provided continuity to identity and a source of self-esteem. Yet the numerous tensions revealed within the stories of living with MS illuminate the complexity of lives and illness. The findings suggest that individuals who have a chronic condition are not simply managing their illness according to their own values and preferred coping repertoire, nor are they simply in receipt of family support. They are likely to be negotiating a dynamic experience of living with their illness, directed by more considerations than their own personal health needs. The family context may be both changing and also resisting change; making illness easier but also complicating the experience; and not only offering care to the affected person but also receiving (even demanding) care in a reciprocal way.

Narrative researchers always need to be mindful that stories may be shaped in response to the perceived interests of the specific audience. It remains possible that themes such as the 'normality of family life' and the 'forebearance of mothers' may have been emphasised by participants to create a common bond with the interviewer (who was also married and a mother of teenage children) and to narrow any supposed social distance. This possibility

cannot really be tested without further interviews being carried out, perhaps conducted by a person with MS.

The tensions within the accounts reveal that coping with MS is a complex task. The narratives describe more than an illness trajectory. Instead, they bear witness to multiple trajectories associated with changing family circumstances, ageing, children's growing maturity, and so on. That a normal biography can co-exist with a disrupted biography has been noted recently with people who have arthritis and other joint problems (Sanders et al., 2002). Perhaps because of the scope of the interviews, the narratives could not easily be classed as progressive or regressive. Gains, losses and normality existed in complex combination.

### **Conclusion**

It is important for researchers and health professionals to be aware that disabled people have caring responsibilities and aspirations, which complicate their task of coping with illness. The illness experience both affects and is affected by the whole family dynamic. The subjective importance of the care-giving role was emphasised at the end of the interview by the most disabled participant:

Roberta: I'm a mum, and a daughter, and a wife ... and along comes my baggage, my baggage is MS, that's my baggage, that's what comes with me.

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