

5 The Functions of ‘Always’ in Women’s Narratives of Living with Multiple Sclerosis: An Exploratory Analysis of Identity Maintenance and Change

FRANCES REYNOLDS

Multiple sclerosis (MS) is a chronic neurological disease that commonly impairs mobility, continence, and levels of energy. The progressive loss of functioning and the unpredictable trajectory of the illness are recognised to threaten identity and create biographical disruption. This paper is based on in-depth qualitative research interviews with six women about their strategies for living with MS. Previous research into identity change (by Mishler, 1999) has noted the regular appearance of ‘always’ in the narratives of people describing major life transitions. Influenced by these observations, the author examined the functions and meanings of this word within the women’s narratives. The analysis revealed that ‘always’ was often used when the women were emphasising the long-lasting beliefs, attitudes, interests and personality characteristics that sustained them in coping with MS (eg. ‘always positive’, ‘always interested in art’). These durable characteristics appeared to provide stability of identity in the midst of change and loss. Some references to ‘always’ marked the presence of strong, reliable supportive relationships (eg. that people were ‘always encouraging’). ‘Always’ was also used in contexts which revealed certain ongoing difficulties and the complexities of coping with illness. They provided insights into the women’s ‘uncomfortable truce’ with MS. These sections tended to have the form ‘always ... but ...’. Whilst not replacing a conventional thematic analysis, this focus upon the use of words and linguistic patterns in the narratives provided rich insights into identity maintenance and identity threat during chronic illness.

Introduction

Multiple sclerosis (MS) is a chronic neurological disease that commonly impairs mobility, continence, and levels of energy, through the demyelination of nerve fibres. It has both progressive and relapsing-remitting patterns, and is

the most common disabling illness affecting young adults. As there is no cure for the disease, people affected by MS require a broad repertoire of coping strategies in order to construct a life having acceptable quality. Part of the challenge appears to be managing the impact of a progressive disabling illness on self and identity. Compared with certain other disabling illnesses, MS appears to have a particularly pernicious effect on well-being (Rao, Huber and Bornstein, 1992; Rudick et al., 1992). Several autobiographical accounts of people affected by MS reveal that they feel gradually robbed of their familiar self and identity, along with their physical functioning and valued occupations (see analyses by Corbin and Strauss, 1987; Monks and Frankenberg, 1995). Identity is not only threatened by the impact on MS on physical functioning. Most people with MS have to retire from work within a few years of diagnosis, and the illness likewise interferes with valued leisure occupations, and domestic roles (Hakim et al., 2000; Jackson and Quaal, 1991; Lundmark and Branholm, 1996). Some people with MS feel as though they have been cast into 'narrative suspense' as potential future selves are contemplated and a new life plan is formulated (Mattingly, 1998).

Much qualitative research into the illness experience - particularly that carried out within the phenomenological perspective - takes a thematic approach to analysis (eg. Barton et al., 1994; Miller, 1997). Phenomenological research embraces the assumption that people provide genuine access into their experiences, interpretations and values through the accounts that they give, within the limits set by the agenda of the interview context (Caelli, 2000). Whilst thematic analysis of illness narratives yields rich insights into the lived experience of illness, some narrative researchers advocate examining the linguistic structure of participants' accounts, and the microanalysis of segments of text (eg. Wengraf, 2001). The form of the story that is told and choice of specific words may suggest issues about which the interviewee has little conscious awareness, and limited editorial control. Therefore such features may provide rich clues to the management of identity.

This study was influenced by an analysis of the stories of identity presented by artists and craftspeople, when reflecting on their vocational choices and career trajectories (Mishler, 1999). Mishler argued that theories of adult development tend to overestimate the continuity and predictability of development. In illustration, he describes a participant's identity as 'neither fixed nor progressively developing but ... continually reshaped and reconfigured in response to his changing circumstances' (p.62). His interviews with artists led him to argue that people have a 'chorus of voices' rather than a 'totalising identity' (p.8). In the narratives of artists and craftspeople concerning their career trajectories, Mishler noted the repeated use of 'always'. Interviewees described 'always' being interested in the arts, 'always painting', or 'always making things'.

Carla Stone, the artist-potter ... tells us at the beginning of the interview that she had never thought of art as an 'option' for the work she would do. Although she had 'always' - the adverbial modifier that recurs again and again in these respondents' accounts - done artwork in childhood and high school, she did not pursue it as a serious activity ... Rather there is a hiatus - a break in the continuity between her early involvement in art and her later decision to make this her life's work. (Mishler, 1999, p.63)

Mishler cautioned that 'always' did not function in the same way for each interviewee. For some, the term marked the integration of art into their lives, whereas for others, its use seemed to draw attention to the more problematic separation of art from daily life and family interests. Nevertheless, Mishler regarded the use of 'always' as functioning as an identity claim, asserting coherence and organisation to identity, and sometimes signalling a struggle with the dual process of accommodating and resisting change. Mishler's work focused on artists, many of whom had taken up art in their later years, thereby undergoing an apparently profound identity shift. Their narrative work in interviews was held to impose coherence and meaning on the changes that had taken place. Influenced by these observations, the author examined the functions and meanings of this word within the narratives of women with MS, to examine whether and how they used the term 'always' in their accounts to make certain identity claims, in a context of managing identity reconstruction during chronic illness. The analysis was not intended to replace a more conventional thematic analysis, but it was hoped that attention to the use of such words and phrases might provide rich hypotheses about the experience and management of identity through all the physical and social changes imposed by MS.

Method

A qualitative study of the lived experience of MS was carried out, with specific reference to the strategies and experiences that enhanced the quality of life and satisfaction of women with MS.

Participants: Following ethical approval, six women with relapsing-remitting or progressive forms of MS were recruited to participate in the study, from invitations placed in a local MS Therapy Centre. They had differing social circumstances, and physical limitations. Three continued to work (part-time) and three had taken early retirement on health grounds. Some of their details are outlined in Table 1:

Table 1: Summary of Participants

Name (Fictitious)	Age	Length of illness	Marital status	Work	Mobility
Hazel	32	10 yr	Single	Financial adviser (part-time)	Walks with a stick
Christine	35	9 yr	Single	Works part-time as a magazine editor	Uses a wheelchair
Elaine	48	>20 yr	Married	Early retirement	Increasing mobility problems
Sue	48	11 yr	Married	Retired from social work	Uses a wheelchair
Jean	48	17 yr	Married	Antiques business (part-time)	Good mobility
Kirsty	49	18 yr	Single	Early retirement from teaching	Wheelchair user - live-in carer

Procedure: The main questions for the interview were given to all participants beforehand, 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. *Data analysis:* As a supplement to a more conventional content analysis, the transcripts were searched for the use of the word ‘always’. Relevant sections of the interview were compiled, and examined for the meanings and functions of this term within the context of the broader narrative. Five major contexts were identified.

Findings

1. Life-long Personal Beliefs, Aspirations, Interests, Skills and Strategies for Living

Many of the participants used 'always' when referring to life-long personal beliefs, interests and other qualities that could be construed as resources for coping with illness, and achieving a satisfying life. The use of 'always' in the narratives also signalled an ongoing commitment to dreams and aspirations, in defiance of the illness. Such long-standing values, interests and aspirations could be interpreted as preserving some continuity of self amid loss and change. Such references also brought the 'person' rather than the disability to the foreground of the interview:

I've always loved craftwork, always loved to see it, always loved to go to galleries
... I just refused to give up (Sue)

In her interview, Sue showed a huge portfolio of artwork, which provided evidence of the extent to which she had become committed to creative occupation since her illness began. She explained how she had revived a long-standing interest in art when her health forced early retirement, and the subsequent experience of empty days. Once she realised that artistic occupation could fill time productively, she described gaining a sense of future, and from then she slowly evolved a positive identity as an 'artist'. Like the artists in Mishler's study, Sue presented her turn to art as a way of coping with illness not as a random discovery, but as grounded in life-long interests. She claimed both continuity in her identity as well as growth.

Other participants also confirmed that the new occupations that were contributing to their quality of life during illness were grounded in earlier (pre-illness) interests. Indeed, some pointed out that they were grateful to MS for presenting an opportunity to engage in activities that they would have had little time for, had illness not led to early retirement:

I was always interested in history so I took an A level {recently} ... One of my dreams was always to do a university course ... (Jean)

Long-standing skills that were not affected by illness also seemed to provide a resource for continuity and life satisfaction:

I like being the editor {of a local magazine} ... I've always been very good with words and I quite enjoy that (Christine)

Long-term positive attitudes to coping with stress, now applied to living with MS, were presented as crucial for enabling the woman to resist the domination of illness over daily life and identity:

I've always been quite positive really. If you think you can do it, you know, you do it! ... I have always believed that independence is the most important thing because at the end of the day, you come into this world alone and you leave alone. You have got to be able to cope. You've got to. (Jean)

I've always thought positively anyway, I'm one of those people that always looks on the bright side. Is the glass half filled with water? I always said it was half full rather than half empty (Hazel)

Such long-standing values were presented as central to the process of coming to terms with illness:

People do say why me? I've always thought well why not you? We're not special. It just happens that way (Jean)

2. Values and Guidance Derived from Parents

In some cases, the use of 'always' in the narratives portrayed the woman's strategies of living with illness as grounded in long-standing values derived from parents and (for one participant) grandparents. Some participants traced the tools they were using to manage life with MS to their parents' ways of dealing with adversity. Because the woman had the role models and moral resources of her family of origin to draw upon, she saw herself as proactively managing the illness experience:

I've always fought against things, I've always been tired {because of MS} and I remember my mum saying to me, I was about 23 at the time ... 'You've got to keep fighting every day of your life' which of course is true (Elaine)

Parent role models and family belief systems did not only contribute to the 'fighting spirit'. Some participants drew upon family interests and expertise when looking for new occupations that could be carried out within the physical limitations imposed by MS. One participant had recently set up a part-time antique jewellery business since retiring from her former career in the police service. She explained that this new occupation was feasible because of the knowledge gained from her childhood:

My mother was always interested in jewellery. So from a young age I have always looked in jewellers windows ... I kind of absorbed it (Jean)

These sections of narrative could be interpreted as locating the women firmly within the continuity of their family history, and a context that provided familiar resources for coping with change and adversity.

3. The Presence of Social Support

Most of the participants used 'always' during at least one point in the interview to refer to highly stable social and spiritual support. Just as the coping strategies that the individual had devised for coping with illness were portrayed as mostly rooted in pre-illness experiences and values, so too support was described as having a long history.

My friends were always there (Christine)

I've always felt that Jesus was there (Elaine)

One participant referred to her former work colleagues as both helpful and also appreciative of her support to them.

That's been another great source of strength as well, because people from there {the former workplace} have been tremendously helpful and, you know, that's been good. Yes, and they've given a lot of help and support and they're always very, very nice and say what a strength I was to them (Kirsty)

This extract serves to tell the listener that the woman is an active participant in her social circle, not to be regarded as 'simply' in receipt of care. Indeed, elsewhere in the interview, Kirsty described how difficult it was for her to have a live-in carer, which she experienced as reducing her control over daily life.

It appears from the major functions of 'always' identified so far in these accounts, that participants were conveying considerable stability in coping dispositions, identity and support structures. From these extracts there was little sign that the women's identity had been profoundly disrupted by illness as they presented themselves as managing their illness with a wide range of familiar resources. However, two further contexts in which 'always' was used betrayed a more complex struggle.

4. Long-Standing Health Problems and Concerns

'Always' was sometimes used to emphasise the profound effects of MS - for example, the experience of severe symptoms, or the anxieties that the condition continually provoked:

The pain was ... pretty drastic ... that was the worst I had had MS ... I always compared it to a tortoise with its shell ripped off, you felt so vulnerable (Jean)

I know what the worst case scenarios could be and it's always in the back of your mind, isn't it? You're thinking 'Oh no, I'm going to end up like this, or end up like that' (Christine)

The microanalysis thereby revealed that the women were not presenting undiluted 'triumphant tales', even though they expressed many positive strategies for limiting the effects of illness on identity and quality of life. As well as being 'always positive', they 'always' faced discomfort and anxiety. There was a co-existence of positive and negative elements in the illness experience.

5. *An Uncomfortable Truce with MS*

In some cases, 'always' was used to mark a contrast - in physical functioning, ways of living, or identity. These extracts sometimes had an 'always ... but' construction:

Although I was always very positive, I didn't really accept it totally (pause) I came to terms {with the illness} about 5 years after I was diagnosed so (pause) but I think that everybody takes their own time, it's because it's not something that goes away, it's there for life (Hazel)

Here an apparent contrast is signalled - between the disposition to be positive, which falters at finally accepting the illness. Given that Hazel seems to take pride in her positive approach to living with MS, as she mentions this several times in the interview, it may have been difficult for her to admit that it was not an easy task to be 'always positive'. A painful contrast between the perceived former self and present capabilities also seems to be conveyed by an extract from another interview:

I always used to be, before I was ill you know, terrifically active. Never a problem multi-tasking. Multi-skilling like mad. And now I just can't do it. Coming to terms with that has taken a long time (Jean)

Another participant, who developed MS at the age of about 37, also used 'always' to refer to her pre-illness life, intimating the change in identity that she was confronting now that she had lost the ability to walk easily:

There was always lots to do, lots of things, but active things (Sue)

One participant suggested that it was easier to be optimistic at the MS Therapy Centre where people understood the problems of the illness. She had found it much more difficult to remain positive in the 'outside world' where people often stigmatised disability:

So I've always been an optimistic person, it's nice to get together with other positive thinking people {at the MS Therapy Centre} and it's also nice to go somewhere you don't have to explain why you stumbled, you know things like {joking} 'Oh dear, I've drunk too much'. It's nice not to have to explain (Hazel)

The struggle to remain 'always optimistic' becomes completely apparent later in the interview:

I would prefer it if people could remember me, it sounds morbid, but if I was to get knocked over tomorrow, I would prefer that people would remember me as 'oh yes, she had that horrible disease but she was always happy', you know, and then if anyone gets diagnosed, they think well it can't be that bad, because Hazel's always happy (Hazel's voice breaks and she becomes tearful)

This microanalysis of the use of 'always' points towards the ongoing struggle between the positive forces of the women's long-term support and coping resources, and the negative forces of illness symptoms and social discrimination which sometimes threaten to overwhelm the woman's determination. Some of the extracts seemed to indicate much ongoing effort to maintain a positive identity.

Discussion

Some interpretations of the meanings and functions of 'always' in the narratives of women with MS have been offered throughout the Findings section. Just as Mishler (1999) found in his study of career trajectories, attention to parts of the narratives containing 'always' provided rich insights into the long-standing psychological and social resources that help people to maintain their familiar identities during chronic illness. Occupational skills, personal interests and family role models that were valued prior to illness continued to function to preserve self and identity. The subjective importance of being positive and adopting a fighting spirit in relation to MS has been noted in previous research (eg. Quinn et al., 1995; Robinson, 1990).

The micro-analysis also provided glimpses of the on-going struggle to maintain a satisfactory life and identity in the context of MS. At best, some participants seemed to maintain an 'uncomfortable truce'. The analysis generally took a phenomenological stance, and assumed that participants were revealing enduring thoughts, experiences and strategies to the interviewer,

rather than presenting a crafted, socially desirable 'self-image'. Nevertheless, caution in interpreting the narratives is needed. Some disabled people feel that they are negatively judged by non-disabled people unless stoical about their impairments (Radley, 1993), and this concern might have encouraged claims that they were 'always positive'. It is also possible that participants were simplifying and increasing the coherence of their 'told story' during the interview, as it is impossible to recount one's life in its full detail during an interview. When for example, participants claimed to be 'always interested in art' or 'always optimistic', they may have been smoothing over the complex flux of experience. Clearly, generalisation from such a small sample is unwise, but the findings certainly suggest issues for further exploration.

In conclusion, the microanalysis of the functions of 'always' in the narratives of women with MS yielded hypotheses about the illness experience that can guide further content analysis and subsequent interviews. According to the segments of narratives analysed, the women presented themselves as drawing upon many long-standing coping resources, attitudes, interests, and role models, thereby maintaining continuities in their identities, even in the midst of a changing lifestyle. Yet sometimes 'always' referred to the pre-illness self and signalled a struggle in accommodating to the changes that illness was imposing upon them.

Acknowledgement

The author is grateful to the participants for sharing their stories and appreciates the financial support of the Brunel University Research Concepts Fund.

References

- Caelli, K. (2000) The changing face of phenomenological research: traditional and American phenomenology in nursing, *Qualitative Health Research*, 10 (3), 366-377.
- Corbin, J. and Strauss, A. (1987) Accompaniments of chronic illness: changes in body, self, biography, and biographical time, *Research in the Sociology of Health Care*, 6, 249-81.
- Hakim, E., Bakheit, A., Bryant, T., Roberts, M., McIntosh-Michaelis, S., Spackman, A., Martin, J. and McLellan, D. (2000) The social impact of multiple sclerosis: a study of 305 patients and their relatives, *Disability and Rehabilitation*, 22 (6) 288-293.
- Jackson, M. and Quaal, C. (1991) Effects of multiple sclerosis on occupational and career patterns, *Axon*, 13 (1), 16-22.

- Lundmark, P. and Branholm, I. (1996) Relationship between occupation and life satisfaction in people with multiple sclerosis, *Disability and Rehabilitation*, 18 (9), 449-453.
- Mattingly, C. (1998) *Healing dramas and clinical plots: the narrative structure of experience*, Cambridge, Cambridge University Press.
- Miller, C. (1997) The lived experience of relapsing multiple sclerosis: a phenomenological study, *Journal of Neuroscience Nursing*, 29 (5) 294-304.
- Mishler, E. (1999) *Storylines: craftartists' narratives of identity*, Cambridge, Mass, Harvard University Press.
- Monks, J. and Frankenberg, R. (1995) Being ill and being me: self, body and time in multiple sclerosis narratives, in B. Ingstad and S. Reynolds-Whyte (Eds), *Disability and Culture* (pp.107-34), Berkeley, University of California Press.
- Quinn, A., Barton, J. and Magilvy, J. (1995) Weathering the storm: metaphors and stories of living with multiple sclerosis, *Rehabilitation Nursing Research*, 4 (1) 19-27.
- Radley, A. (1993) The role of metaphor in adjustment to chronic illness, in A. Radley (Ed) *Worlds of illness: biographical and cultural perspectives on health and disease*, (pp.109-123), London, Routledge.
- Rao, S., Huber, S. and Bornstein, R. (1992) Emotional changes with multiple sclerosis and Parkinson's disease. *Journal of Consulting and Clinical Psychology*, 60, 369-378.
- Robinson, I. (1990) Personal narratives, social careers and medical courses: analyzing life trajectories in autobiographies of people with multiple sclerosis, *Social Science and Medicine*, 30 (11) 1173-1186.
- Rudick, R., Miller, D., Clough, J., Gragg, L. and Farmer, R (1992) Quality of life in multiple sclerosis: comparison with inflammatory bowel disease and rheumatoid arthritis, *Archives of Neurology*, 49, 1237-1242.
- Wengraf, T. (2001) *Qualitative research interviewing: biographic narrative and semi-structured methods*, London, Sage.

