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## Encountering the downward phase: biographical work in people with multiple sclerosis living at home

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### Abstract

This qualitative study examines how individuals in an advanced stage of multiple sclerosis (MS) who live at home, accommodate to their illness. The downward phase in the illness trajectory of MS often consists of a lengthy period of gradual decline. According to Corbin and Strauss's framework, accommodation is conceptualized as biographical work that refers to the actions taken to retain control over the life course and to give life meaning again.

For our purpose semi-structured interviews with 22 people with MS were conducted and compared with 21 interviews with their family caregivers. The analysis consisted of fragmenting and connecting the data and involved close reading and constant comparison.

The continuity of biography is at risk since body and performance failures lead to the loss of salient aspects of self. Participants interpret MS as an all-encompassing illness and emphasize the process of having to give up everything. Four case stories are described to demonstrate the complex intertwining of the biographical processes and to show the range in biographical accommodation. Some patients are capable of putting their lives back together again, while others retreat or do not consider MS a part of their lives. The unpredictable course of MS makes it impossible to give new direction to the life course. © 2002 Elsevier Science Ltd. All rights reserved.

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### Introduction

Multiple sclerosis (MS) is a severe neurological disease, which not only has a profound physical effect on the lives of the sufferers but also has far-reaching psychological and social implications (Eklund & MacDonald, 1991; Robinson, 1988). MS primarily affects young adults and two to three times as many females as males (Zwanikken, 1997). In the Netherlands, an estimated 15,000 people are afflicted with MS, around 4000 of whom live at home while they are incapacitated and in need of help (Netherlands Multiple Sclerosis Society, 1997). The course of MS is unpredictable and

can lead to numerous and variable symptoms, including impaired mobility, weakness, muscle spasms, sexual dysfunction, pain, difficulty in communication, blurred vision and loss of control over bowel and bladder function (Zwanikken, 1997). Despite encountering deterioration, some patients are capable of regaining some kind of balance in their lives and of integrating the illness into the fabric of their being. For others, MS constitutes a devastating experience that brings about an insuperable discontinuity in their lives (Braham, Houser, Cline, & Posner, 1975; Robinson, 1990; Favro Marks, & Millard, 1990; Eklund & MacDonald, 1991). This paper addresses accommodation to MS by patients in an advanced stage of their illness.

Accommodation is conceptualized by Corbin and Strauss (1988, p. 255) as biographical work that consists of actions aimed at achieving a sense of control and

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balance in life, as well as giving life continuity and meaning despite the illness and the changes it brings. This is in line with the evidence from other researchers that severe disability and chronic illness can bring about substantial changes in the patient's identity (Wiener, 1975; Bury, 1982; Charmaz, 1983; Kelly, 1992; Nijhof, 1995). Besides biographical work, the authors distinguish everyday work and illness work, which are both related to the management of the illness in daily life. All activities of patients, family members and health care providers are explicitly referred to as types of work, to express their efforts to influence the illness course. It is the very premise of Corbin and Strauss's concept of the illness trajectory that even if the course of the disease itself cannot be modified the illness course can be shaped and managed. As disabilities become increasingly severe, biographical work takes precedence over both the other lines of work. Progressive disability and the descending course of the illness indicate the downward phase of the illness trajectory, which in MS often consists of a lengthy period of gradual decline.

In this study Corbin and Strauss's grounded theory on managing chronic illness at home has been chosen to focus the research questions and guide the empirical investigation. For this reason there follows an explanation of a number of essential concepts from their framework. Corbin and Strauss distinguish between three dimensions of a person's biography or life course: body, biographical time and conceptions of self (BBC). The views of oneself evolve in accordance with an ability to perform the tasks associated with the various aspects of self. Illness can lead to body failure and prevent people from carrying out all of the tasks they used to perform. As a consequence the connection between the BBC is shattered and causes the person to lose his feeling of wholeness or broader identity (Corbin & Strauss, 1988). For example, being a journalist requires the ability to operate a keyboard manually. But when MS afflicts the hand function it becomes impossible to type and this can make a person give up the journalistic writing i.e. this aspect of self. As a consequence the person might question who he or she is and be in the future now that he or she is no longer the journalist one used to be.

Biographical work constitutes four processes: (1) contextualizing (incorporating the illness trajectory into biography), (2) coming to terms (arriving at some degree of understanding and acceptance of the biographical consequences of failed performances), (3) reconstituting identity (reintegrating identity into a new feeling of wholeness around the limitations in performance) and (4) recasting biography (giving new directions to biography). Biographical work is aimed at restoring the link between the three dimensions of the BBC. The four types of work are separate but overlapping and they can only be distinguished at an analytical level since

in practice they are intertwined and developing at the same time.

The characteristics of the illness influence the nature and the amount of biographical work required (see for example Anderson & Bury, 1988; Roth & Conrad, 1987). For MS, the young age at the onset of the disease (usually between 20 and 40), the duration of the disease (on average 25.7 years, Donker, Foets, & Spreeuwenberg, 1996), the unpredictable course of the disease and its capacity to disable seem to account for the many challenges of adjustment for patients and their families (Davis, 1973; Robinson, 1988). Research has shown that MS patients tend to respond to these daunting prospects by resisting or fighting the disease rather than denying, accepting or integrating it into their lives (Brooks & Matson, 1987; Robinson, 1988). Robinson (1988) suggests that these responses might be explained by the absence so far, of an accepted scientific explanation and cure for the disease. Smeltzer (1991) adds that treatment of MS rarely involves high technology interventions and it therefore leaves patients to draw on their own resources, especially when it comes to controlling their state of mind.

The objective of this study is to ascertain how people in the advanced stages of MS accommodate to their illness. It examines how MS induces biographical work in terms of BBC. It then goes on to describe what this biographical work involves in terms of the four different types of work and touches on the differences between patients. The selection of MS patients in a downward phase offers the opportunity to study accommodation in a situation where the biographical challenges are evident and maximized (Morse, 1999). The study attempts to contribute to the knowledge of disability and identity by adding the experiences of a very specific group of chronically ill persons. The use of the trajectory model with its notion of biographical work to understand the ill persons' reactions and beliefs, as Smeltzer (1991) acknowledges, has the potential to inform health care providers about the needs for support of these persons. Services that are based on an inside understanding of the difficult biographical processes the ill persons are in, can help them in their striving to maintain or regain some degree of control over their lives.

## Research methods

### *Procedure*

Access to MS patients was gained through five home care organizations and nine members of the steering committee installed at the start of the project to supervise the research. The members of the committee all had various connections to MS, some as MS patients or caregivers themselves and others, such as a

neurologist, nurse, and committee member of the Netherlands Multiple Sclerosis Society and the National Organization of Caregivers, as professionals. Each was asked to recruit two persons with MS to participate, as well as the persons whom they designated as the primary caregiver. Some could meet these agreements, others could not, for example one of the neurologists who had to go through a very lengthy procedure of consent.

This research was introduced as a study into the experiences of persons with MS and into how they managed at home. Potential participants were also told to expect an interview in a conversational style since the researchers were interested in what they had to say. People who agreed to an interview were motivated to share their knowledge with other patients, wanted to bring MS to the attention of a wider public and acknowledged the scientific character of the study as it came from the university.

The recruiters were instructed by the researchers to include people who live at home, who are dependent on care as a result of MS and who receive care from family members. For that purpose they received an information leaflet in which the selection criteria and the reasons for them were explained. In the meetings with the steering committee questions concerning recruitment and access were discussed. With a view to exploring the research questions, they were asked to select patients with differing characteristics with regard to age, sex, duration of the disease and its course until that moment. These characteristics were our first tool to reach a study group which reflected variation on the topic of our interest, although it was understood that the selection in qualitative research should be purposeful and suitable to make theoretical advances in relation to the research question (Mason, 1996). Once that more information had been obtained from the first ten patients, the final selection of patients was guided by the themes that were important in the preliminary analysis. Recruiters were then asked to seek participants with specific experiences, as for instance the loss of worthwhile social activities, coming to terms with the illness or problems with dealing with help.

### *Study participants*

Twenty-two MS patients, thirteen female and nine male, were interviewed. All were living in the Netherlands or Belgium. Eighteen were married to, and living with, their spouses. Of the other four (one man and three women) two had never been married, one was widowed and one divorced. The ages of the patients ranged from 31 to 78, with an average age of 55.

Ten people were forced to stop working because of MS. One of them did part-time voluntary work for 2 days instead. Seven of the women were housewives, four people were retired and one was employed part-time.

Formerly, of those in paid employment, five of the patients might be described as white-collar or clerical (sales representative, secretary, estate agent). Four were professionals (e.g. teacher, information technology). Three had been manual workers (e.g. worker in textiles, chauffeur) and two had academic qualifications (university researcher).

The patients had been diagnosed with MS for a mean of 19 years. The periods of time since diagnosis ranged between 4 and 54 years. Of a total of six possible Activities of Daily Living (ADL: bathing, dressing, transfer, toileting, continence care and feeding), patients needed help or supervision with an average of 5 out of 6 activities. With the exception of two people who were able to walk inside their homes, all patients needed a wheelchair and six people were bedridden. Fourteen people could not use their arms and hands adequately as a result of spasms or weakness, eleven people complained of fatigue and ten had poor eyesight. Four had difficulty talking or swallowing, two had memory problems and two were in pain. Sometimes the basic socio-demographic data (age, sex, numbers of children, employment and need of help with daily activities) could be derived from the interviews, if not, they were inquired after the end of the interview and filled in on the contact summary sheet.

The eighteen married patients all indicated that their spouses were their primary caregivers. The other four identified a friend, a brother, parents and a son and daughter-in-law. Eighteen patients had children. In seven of the families, the children lived at home. Nineteen patients received help from home care nurses and seventeen from housekeeping services. Only one patient managed alone with his spouse and did not receive any professional help.

### *Data collection*

Qualitative interviewing was used to gain access to the participants' personal stories. Visiting them in their homes allowed us to observe the consequences of a chronic illness at first hand. The interview method allowed the interviewer to ask the participants to elaborate on former experiences as well as on their present ones. Our introduction and first questions ("What concerns do you have at this stage of your illness and how do you deal with them?") was directly seized upon by the respondent and set the stage for the rest of the interview. Important topics, derived from both literature, the chosen framework and the expertise of the research team, were the history of the illness in terms of the body and performance, what life was like in the past, changes since being diagnosed with MS, the challenges at this particular stage, ways of coping with it and the view of the future.

All the interviews were tape-recorded and transcribed. Directly after the interview a contact summary sheet was made, on which the most important themes in the interview were noted, as well as reflections on our roles as interviewers (Miles & Huberman, 1984). The transcriptions and the reflections were discussed afterwards. Thus the other researchers in the team kept track with the progress of the interviews and coached the interviewers technically as well as emotionally, since the team members were by definition more distanced to the participants than the interviewers. They checked, for example, whether the interview questions and topics needed any revision in order to provide adequate answers to the research questions. The interviews were conducted by two different interviewers. One interviewer [HB] conducted the first interviews with 12 patients, the other did the remaining ones. The second interviewer, who was of the same age and sex as the other one, read every previous interview and used the same list of topics. This obviously 'socialised' her to conduct interviews in the same way, which resulted in few inter-observer variations.

### Analysis

The analysis involved the approximately 300 pages of transcribed interviews of the patients alone. The interviews with the MS patients were compared with the interviews of their caregivers to obtain a deeper understanding of the patient's biography within the context of the adjustment of the family as a whole (Banyard & Graham-Bermann, 1993). The various backgrounds of the members of the research team, which included nursing science, sociology and psychology, allowed the data to be interpreted from different angles and constituted researcher triangulation (Kimchi, Polivka, & Stevenson, 1991).

The analysis consisted of two activities that kept each other in equilibrium, namely fragmenting and connecting (Dey, 1993). In the first activity the component parts of each interview were separated out and labelled with codes. This involved close reading, line-by-line analysis and constant comparison (Strauss & Corbin, 1998). The process of code-and-retrieve was conducted using the software program winMAX (Kuckartz, 1998). Our coding system was created by moving back and forth between the concepts of the framework, our interviews and the preliminary analysis. Categories such as 'body failure', 'conceptions of self' and 'coming to terms' were clearly informed by the framework, whereas 'striving to stay at home', 'all-embracing' and 'turning points' emerged from the data. Later on we began to place the codes into what we felt to be the major categories. Thus, 'breadwinner', 'grandma' and 'slowcoach' were abstracted to the level of 'concepts of self'. Finding new friends', 'avoiding information about MS' and 'asking

for adequate help' were all placed in the category 'challenges'.

An interpretive reading of the interviews was conducted, which called for our active involvement in inferring meaning from the data (Mason, 1996). For example, respondents mentioned that 'all was lost' and 'nothing stayed the same' and gave clear descriptions of the changes MS had wrought in their lives and in the lives of their families. From this it was derived that patients had to accommodate to a 'greedy illness' which left neither their present functioning nor their biographical past and future unaffected.

The second activity in the analysis process consisted of interpreting the parts as a whole and connecting the pieces of one case together. From the beginning it struck us that people had very different ways of accommodating. After fragmenting the data it was apparent, for example, that participants reached various levels of coming to terms with MS. To gain a sense of the distinctiveness of the combinations of the four biographical processes people were involved in, it was necessary to focus on the case stories as a whole. A chart was used as an analytical tool. The elaboration of the pattern extended when it was discovered that almost all patients had a motto that summarized their way of accommodating to MS.

The construction of the biographical case-stories originated in the contact summary sheets on which the illness trajectory was noted down as the interviewee had pointed it out in headlines. The biographies should be considered as interpretations of life with the illness, not as descriptions of it (Nijhof, 1995). The participants choose their own words and are likely to be influenced by the interview situation in which they were prompted to reflect on their life with the illness. The life stories are not assembled in order to find out the course of the participants' life, but to render their own interpretations of it with regard to the biographical work. The data extracts that are presented were selected to document the conceptualisation of biographical processes and to offer the possibility of control. Quoting is also done to provide the reader with a feeling of the struggles people are in and to make the different perspectives people develop of their illness understandable.

To provide a closer view of particular biographical processes four cases have been selected and are described in their entirety. These case stories were selected because they reveal much about the complex intertwining of the biographical processes and because they reflect the range of biographical accommodation. Before we go on to look at the case stories, the common cross-sectional themes are presented in relation to the biographical consequences of the downward phase of MS. All the names used are pseudonyms.

### The downward phase of MS: giving up everything

In this section we demonstrate how MS affects the three concepts of BBC (body, biographical time and conceptions of self) and how this induces biographical work.

#### *Body and performance failure*

In the interviews with people with MS, references to their bodies and body failure are apparent. Some make a chronological inventory of their ailments, such as: 'It started in a toe, and then my legs were afflicted. My eyes are very bad. And now my hands are totally paralysed'. However, most patients immediately move on to mention the activities they cannot perform anymore as a consequence of their ailments. Like Mrs. Stacey who saw the illness slowly creep up till her arms also became affected. This stopped her from playing with her grandchildren in a way that she always looked forward to:

Well, I can't complain, MS does not cause me any pain. But psychologically, my head is still working fine and my upper limbs were last to go. So I can't steer anymore, I can't eat by myself and I couldn't even shake your hand when you came in. That part of MS is very hateful. You are a prisoner of your own body. What makes it worse is that I used to be very healthy. I kept my household well and I raised my six children. And now I would like to pamper my grandchildren and have fun with them. I am resigned to the physical part, but lately I can't stand the fact that I am afflicted.

The faculties that are still intact are very precious to people, because they compensate for the lost ones. Loss of leg function can be compensated by using one's arms to move a wheelchair, thereby regaining some of the lost mobility but by the same token, the loss of the last remaining functions becomes twice as difficult to bear. The patients interviewed dreaded losing their eyesight, because it would have serious consequences for their mobility and it would deprive them of the pastimes of reading and watching TV.

On the surface, appearance does not seem to be a major performance issue for people with MS. Their bodies appear undamaged and they are not subject to any disfigurement whatsoever. However, a closer look reveals that appearance can certainly be an issue. When the patients walk they have an unsteady gait or sway like a drunk and they have to use walking aids or a wheelchair for longer distances. Some people have to be fed or use a straw, which stands out when drinking coffee or alcoholic beverages in a public place. This often

prompts remarks from others that cause the patients to feel ashamed (see also Nijhof, 1995).

At the advanced stage of the illness, most MS patients have incontinence catheters and urinary bags that are invisible most of the time, because they can be inconspicuously tied to the patient's leg when he or she is wearing a pair of trousers. From the interviews and other studies as well (Toombs, 1992; Kelly, 1991), it is known that incontinence causes deep humiliation and shame and that patients always keep some fear that something will go wrong with the appliances they use. However, a catheter can also allow the patient to re-enter public life again. Seventy-one-year-old Mrs. Trumpet could not leave the house because she was always 'soaked and had to sit on a plastic bag'. The catheter suggested to her by her doctor allowed her to go outside and resume her social activities.

Incapacity to act can be perceived as a performance failure and cause shame even without the presence of others. The patient's performance fails according to his or her own personal standards. A telling example of this is the body lift. It is mostly used in the privacy of people's homes, yet our data show that it has a powerful effect on the person's dignity. One man compares himself with a baby carried in a stork's beak and another sees himself diminished like a bale of straw.

#### *Biographical time: the mental time map*

Most respondents have a fairly detailed mental map of the time frame of their decline. Biographical time is important to refer to life stages that have been entangled with the course of the illness since the first complaints and the diagnosis. Some major events mark the course of the illness, such as having to resort to a wheelchair, giving up work, selling the car or an unexpected development like the loss of the speech function. More often patients mention smaller functions they saw disappear slowly, some of which even went unnoticed by others. In the following quote from Mrs. Becker it becomes clear that the illness course and life course are intertwined.

My daughter married in 1989 and then I still did everything. I was sitting in the wheelchair, but I did everything: washing, ironing, cooking, everything, taking care of myself, keeping house, everything. Since 1992 I haven't been able to do it anymore. I had to give up everything I used to do. So, my daughter was never confronted with this. And it was only at New Year when I had a high fever and could not sit up straight anymore, that she saw that my illness is still deteriorating. But sometimes I have the impression that she thinks that everything has stayed the same as when she still lived here.

The interviews contain numerous examples of backward and forward reviews, also referred to as the reflective parts of actions (Corbin & Strauss, 1988). In backward reviews people look back at certain aspects of their lives in the light of the present. One woman, who has had much difficulty in accommodating to her almost bedridden life, looked back at a life full of activity and was happy that the illness only began at the age of 47. Sometimes people regret certain actions, like the interviewee who had all her teeth taken out, because someone told her that bad teeth were connected with MS. Forward reviews, like mental rehearsals and daydreams, are more problematic because of the unpredictability of the illness course. They mostly contain lost plans, such as raising a family, being promoted, being a good grandmother, travelling, saving for retirement and so on. It is these mundane wishes that are made impossible and destroyed by MS.

There are few people who believe that they can benefit from a cure should one be found. Some were even denied the chance to participate in medical trials because they were too old or their physical condition too poor. Some still nursed the hope that their deterioration would slow down and that their mental faculties, hands, eyesight and voice would be left unaffected. One participant who was wheelchair-bound told us that she still walked in her dreams. When her therapist told her that this was preventing her from coming to terms with the illness, she reprimanded him and told him that she still had hope as long as she could walk in her dreams.

The remaining wish for all the participants was to stay at home for as long as possible. Most interviewees dreaded the idea of being admitted to a nursing home, as this for them was the ultimate symbol of being discarded and worthless. The long-term possibility of remaining at home is very uncertain, as it depends not only on the deterioration in the condition of the person with MS but also on the willingness and capacities of the family caregivers (Duijnste & Boeije, 1998).

#### *Conceptions of self: from being active to becoming dependent*

With the loss of physical faculties and performance patients cannot carry out all of the tasks they once considered worthwhile and took for granted in their lives. As such, these losses pose serious biographical risks. MS transforms them from active persons into dependent ones. Whether they raised their family, took part in business, were just busy people or liked active holidays, now they have to be cared for and have lost a great deal of their independence.

When they were growing up, Mrs. Brown's two children hardly noticed that she was ill as she could still drive, take them to school, prepare their meals and so on. Now, 21 years later, she needs others to help her take

care of her physical needs, which hits hard at her concept of self as someone who always cared for others.

There is not much left anymore, so what remains I try to do as well as I can. Reading a book, resting a bit. My husband was an estate agent and I used to do his paper work, I answered the phone, did the book-keeping. But as the years have gone on, all that has disappeared and my husband has taken over everything. Everyone has to take care of me. When I want to move my leg, I have to ask. "Be careful with my legs, my hip there, my head over there, my pillow". All these small things, every day, three or four times a day. Always the same.

Mr. Reed who experienced a rapid downhill course, described how MS robbed him of his salient concepts of self. As a sales representative he regularly visited all the business departments in his work area and was known among his colleagues for his humour and companionable company. Within a year he was unable to walk or drive his car anymore. He lost his job and as a consequence lost contact with most of his colleagues. His wife cares for him and has taken over the gardening and financial administration, tasks that Mr. Reed considers to be a man's job. He was always the life and soul of parties but he cannot live up to that image anymore. So MS stripped him of a wide variety of self-concepts: his masculinity, his capacity to care for his wife, his status as a good driver, a fine colleague and a welcome guest at parties. They were replaced with concepts of someone whom life has treated unfairly, who is bored, cannot do anything and who has to be cared for.

Relating these effects of MS to the three elements of the BBC deepens the understanding of the participants' interpretation of MS as an all-embracing illness. With words like 'all', 'nothing', '100 per cent', 'everything' and 'complete' they express that no part of their lives, whether it be their bodies, performance or concept of self along the time line, has remained unaffected by MS. Life as they knew it has in effect been discontinued and they have been left to deal with what remains. In the next section we turn our attention to the ways in which people have tried to put their lives back together again.

#### **Biographical work: four case stories**

In this section we present four portraits of people with MS. They have achieved each type of biographical work to a different degree and in the combination of types, they represent a range of biographical work. Each pattern is labelled with the motto that the person uses to summarize his or her way of accommodating to the illness: *I try to make the most of it, MS will never have the*

*upper hand, I allow MS to take control of me and I have nothing to do with MS.*

*I try to make the most of it*

My body of course prevents me from doing certain things. Most people admire me because I am still optimistic and I keep laughing all the same. In spite of these worries I enjoy life. Yes, every day, I still enjoy it very much. I have a life of my own. I look forward to the next day, when once again there are nice things planned, only nice things in fact, and nice people.

*BBC:* This is Marc talking, a man in his early thirties who learned 5 years ago that he was afflicted with MS and has deteriorated very rapidly since then. His body failure is apparent: he is wheelchair-bound, has little energy and poor eyesight, he has trouble swallowing and is incontinent. A number of epileptic attacks have meant that his memory regularly fails him. As time went by he lost valuable aspects of self. He could not pursue his hobby of windsurfing anymore and he could no longer drive his car. He struggled to keep working but when he could not perform as well as he wanted, he was declared unfit to work.

*Contextualizing:* When he first heard he had MS, Marc did not want to have anything to do with the disease. He ignored invitations from the MS Society, because he could not identify with the people with their wheelchairs and crutches. After attending their meetings once or twice, he discovered that the members were more than just their illness and were actually very nice people, many of them young. At that moment he realized that MS was going to be a part of *his* life too.

When he needed a walker, he was embarrassed because he felt that such things did not apply to him. Later on, he realized that such aids could enlarge his shrunken world and he stopped caring about other people's reactions to his appearance or his performance. He incorporated the aids into his biography. He even saw it as a challenge to be allocated a scoot mobile, which is an electric device that allows him independent transportation for short distances outdoors.

In a similar vein he incorporated the help he needed to care for himself. He sees the family, friends, nurses and cabdrivers who help him as sources of social contact. Marc thought it would be a challenge to maintain his social network and is surprised that his friends do not treat him as a disabled person. He appreciates them for this. It helps him to contextualize MS, while at the same time maintaining aspects of self that have nothing to do with the illness.

Looking ahead, Marc is afraid that he will grow apart from the people around him as they will soon have children to look after. All things considered, he thinks

the future will not turn out to be too bad. It amazes him that being single does not upset him anymore. He accepts the fact that he is not participating in society, as he would have done had he been healthy.

*Coming to terms:* Marc says he has come to terms with MS. Of course, he did not ask for the disease but now it's there, he is pretty much resigned to it. 'That's just the way it is' and 'you have the disease and that's all there is to it' are expressions he uses to convey this idea. His fundamental attitude is to try to make the most of life. An aspect he finds more difficult to accept is that, as a grown man, he has to rely on his parents and cannot manage on his own. They have taken over his housework and shopping and they structure his day.

Corbin and Strauss (1988) describe how some people suffering from chronic illness can even reach a stage of transcendence, which means that they have found a way to overcome their bodies in such a way that they are able to find real joy in living again. This seems to apply to Marc who likes to refer to MS not as a disease but as something he has to live with. His pleasure in life takes precedence over the requirements of his medication and of 'being a good patient'. Listening to music, watching TV, humour and having fun with others make him enjoy life:

I play cards with a group of friends. And that is always so enjoyable. Because I have these problems with my eyesight, the tables are arranged so that I am as close as possible and my cards are a bit bigger. I am not at all a bad player, but that's not what it's all about. It is just for fun, having a good laugh with each other.

As he says himself, he has been an optimistic person all his life and tries to think positively.

*Identity reconstitution:* Reconstitution is the process of regaining a sense of wholeness that is lost when the links of the BBC are shattered. This has to do with developing and sustaining valued aspects of self. Marc meets and counsels newly diagnosed MS patients in his region and this is very meaningful to him. He has given new salience to his still intact relationships with his parents and his friends. He dreaded the prospect of sitting at home, but to his own surprise he now appreciates his leisure:

When I was working I was almost a workaholic. So I thought that I would go crazy sitting at home all day. But I still know how to enjoy things, it's wonderful having all these days off. Beforehand, you don't expect that to happen, but I've got such nice people around me and I often have visitors. That never seems to stop. I can open the doors with my remote control from my bedroom, which is ideal. I have contact with all kinds of people, including fellow sufferers.

*Recasting of biography:* Until now Marc has been able to accommodate rather well. However, his rapid decline now troubles him. Admission to a nursing home seems inevitable in the near future, since his parents are not able to take him into their own home to look after him. Biographical recasting, which means giving direction to the future biography, is impossible at this moment, as there seems to be no way out, only an undesirable end.

#### *MS will never have the upper hand*

There is not going to be a cure for me. Things aren't going to change, so I might as well believe that things are better, that I like the situation even more now than I did a few years ago and maybe even that I am happy. In comparison with a few years ago I am reasonably satisfied with everything. I have my own life back on track again. I decide what I do, what I want and what I don't want. I will not let MS rule over me.

*BBC:* The above quote comes from Mrs. Ratcliff, who is 58 years old and who has had MS for 25 years. The first symptoms were back pain, tingling in her arms and tiredness. MS was diagnosed within a year. Soon afterwards, she broke off her engagement and lost her job as a teacher. Now, she has difficulty walking and uses a wheelchair. One year ago, she was told that she had breast cancer, from which she recovered after treatment. She is experiencing a slow deterioration mainly due to fatigue and sometimes unbearable pain in her bladder.

*Contextualizing:* When the doctors suspected MS, she went into a state of non-integration. She was completely devastated by the diagnosis and the loss of her job. Her parents let her live with them again and in her own words she 'let herself go'. For 2 years, she retreated and concentrated on the actual and potential lost aspects of self. The breakthrough came when a neurologist told her that she did not need to be dependent on her parents and that she could regain a life of her own. She understood that she was letting MS determine the course of her life and she felt challenged to turn the tide:

At first, MS affected me very badly. I lay in bed most of the time. In the beginning I couldn't accept it. I mean, what is accepting anyway? I couldn't stand it, I thought that there was nothing for me to do any way. Looking back, I think I did not fight that idea. (...) I was not leading my own life. I let it be determined by MS. And now I rule over MS. I have something to say about MS and MS doesn't have anything to say about me. Of course, you never really know how well you'll be able to keep up a positive attitude like that.

From then on MS was a part of her life, but did not dominate it. When she moved out from her parent's

house and went to live on her own again, she wrote on her change of address card that she had made a fresh start. She discovered which aspects of self remained or could be regained in order to provide her with some biographical continuity. Her family, especially her brother who provides care and her friends help her to lead as normal a life as possible since they do not treat her as an MS patient. For instance, she prepares dinner for friends just like she would if she was healthy. Sometimes she pushes her body to the limit, wanting to perform normally instead of giving in to limitations and pain.

*Coming to terms:* Mrs. Ratcliff has accepted MS as something she has to live with but not as something she has voluntarily chosen to live with. She comments: 'I was not offered it because then I could have refused it'. Her personal philosophy is that MS will never have the upper hand and that she is in the driver's seat where her own life is concerned. For her, fighting the disease means that she makes her own decisions and does not give way to pain and fatigue in her body.

She was living in a state of relative acceptance of MS when she was diagnosed with breast cancer. This constituted another devastating blow. At first, she became very angry because she could not grasp why she had to suffer from two such serious illnesses. Soon after a period of mourning, she became calm again, because she had been through the same process before. She wanted to continue with her life. She is convinced that she was able to cope reasonably well with her cancer because she had already learnt to tackle MS. She is satisfied with how things are going now, but she is not as joyful and full of life as Marc is.

*Identity reconstitution:* Mrs. Ratcliff gave new salience to old and worthwhile relationships and activities. There were no real new aspects added to her life. Some years ago, she heard a programme on the radio in which people were asked if they were happy. She realized that she was fairly satisfied with her life compared with some years before, even though things are not as good as they were before MS and she originally wanted different things from life. To some extent there is a feeling of wholeness again.

*Biographical recasting:* Mrs. Ratcliff has become stronger and this gives her hope for the future. With her physical condition waning, it demands more of an effort to accommodate. But she knows she has learnt to carry on and to deal with matters.

#### *I allow MS to take control over me*

My doctor tells me that I only have energy for 1 h, and I have to make do with that for a whole day. I don't do anything anymore. I can't bring myself to do anything. I just let it go. What does it matter? But sometimes it is very hard. (...) I am wholly absorbed



in MS and I let it take control over me. I do not reproach myself for not resisting it. I simply let it go.

*BBC:* Mr. Cunningham, who is 43, has known since 1993 that he is afflicted with MS, but he has had symptoms for much longer. Over the last 5 years he has slowly deteriorated. He still has negative memories of his visits to the hospital, when staff did not take his symptoms seriously and refused to do certain diagnostic tests. When the weather is warm his legs give out. He is tired all the time, his hands and eyes are affected and he has trouble concentrating. Because of his disabilities he lost his job as a professional chauffeur and his contact with family and friends.

*Contextualizing:* Since the activities that were worthwhile for him have been abandoned there is not much left. When he noticed that his performance was failing, he gave up on everything else as well. Mr. Cunningham and his wife had to move to a more easily accessible house, thereby exchanging their familiar neighbourhood for a strange one. He did not succeed in building up new neighbourhood relationships. His wife is actively involved in the MS Society but he himself has no contact with fellow sufferers. When he compares himself to his fellow sufferers he sees himself as less active and a slowcoach:

Yeah, those people at the MS Society are so active and I am envious of that sometimes. I would like that too, I really would. But I'm much more of a slowcoach. I can't bring myself to do it. I don't know how to deal with it. No, I don't know how.

He is very disappointed in his family and friends who have abandoned him since he became ill.

*Coming to terms:* Mr. Cunningham finds living with MS very hard. He cannot accept that his wife has to do all the things that he cannot do anymore. It makes him feel helpless. He became demoralized when the diagnosis was finally revealed and the consequences of the illness increased. Since that moment MS has slowly absorbed him. He cannot close the gap between his present health status and state of being and his former self-image, when he felt appreciated:

Before, I could do everything and in my job I had to rely on my own resources and on my colleagues. And that always went well. But now, my wife has to drill holes in the wall because I can't use a hammer and nails and that is hard for a man to take. Then I think, why bother doing anything anymore. (...) I am a much quieter person now. I used to talk much more, I was much more companionable. I had more stories to tell and that is getting less now. I feel sad more often. That's how it feels, I am empty. I cannot get a hold on it; I just cannot grasp it.

*Identity reconstitution:* MS was too big a challenge for Mr. Cunningham. He is not capable of putting his life back together again. There is a disengagement from all that was meaningful to him and no new worthwhile aspects have been added. Sometimes his own attitude bothers him and he feels guilty about not undertaking anything anymore. Because he cannot get to grips with his situation, he has given up and withdraws into himself.

*Recasting biography:* Mr. Cunningham is not in control of his disease. He is shattered by the illness experience. MS has overwhelmed him and he lacks the strength and energy to resist. The only things that boost his spirits are his grandchild and driving his car for short distances. Daily life does not bring him any joy and he feels that there is no way out.

#### *I have nothing to do with MS*

I hate that word (MS), I hate that disease. In my view, I think the only way to stop it getting to you is to be joyful. At least, I don't want it to get to me. I'll never let them see that I am in pain or anything like that. I don't talk about it to anybody, because I don't want to have anything to do with it. If I do, I get terribly upset and everything comes up again. I have always cried at night and laughed during the daytime. That is how I deal with it.

*BBC:* Mrs. Newcomb is 70 and lives with her husband. Together they have three children. Fifteen years ago she was told that she had MS. After that her physical condition rapidly deteriorated and she became increasingly dependent on help for her personal care. She is incontinent. She can no longer walk or stand, and she now finds it difficult to use her hands. She often has painful spasms in her legs. Several of her family members, including two of her sisters, suffered from MS.

*Contextualization:* Mrs. Newcomb keeps MS separate from the rest of her biography as far as possible. She wants to banish MS from her life and to erase it from her thoughts. The diagnosis was kept from her for years by her husband and her neurologist. They were of the opinion that the announcement would usher in her undoing. Deep in her heart, Mrs. Newcomb always knew that her symptoms were due to MS because she recognized them from her sisters' cases. However, she is glad that she was not told sooner because that enabled her to ignore it for many years.

When she was officially given the diagnosis, she could not ignore it anymore and she lost courage. Only when the symptoms could no longer be covered up, did she tell other people about her illness. As the disease progressed and the consequences were forced on her, it became more difficult to turn away from it. All that was worthwhile to her has been lost:

The worst part is that I can no longer do what I always did. I was always in the thick of things. I was always working, and we went out a lot, we went for nights out. And all that is gone (...). You cannot walk anymore. In the beginning I did some knitting and needlework but now I cannot do that anymore. Reading and watching television, that is all you can do. I did everything, knitting, everything. And suddenly, all that ends!

*Coming to terms:* MS has not been given a place in her life. She cannot accept the illness or its consequences, such as the loss of activities, being wheelchair bound and dependent on others. She feels ashamed of herself. In her eyes she does not deserve MS and she feels aggrieved and victimized. She hates MS so much that she will not even pronounce the words.

*Identity reconstitution:* There is no sense of wholeness in Mrs. Newcomb's case. This is particularly due to the fact that she presents herself to other people as a happy and cheerful person and masks her real sorrow and fear. She only cries at night. She has flashbacks and nightmares of the way her most beloved sister suffered of MS and eventually died. This event has caused such an existential fear that she cannot live with the idea of being a victim of MS herself.

She avoids any confrontation with the illness. She does not read about MS or watch TV programmes that remind her of MS. She shies away from contact with fellow sufferers. She cherishes the company of people who do not talk about the disease. She only enjoys activities that divert her in such a way that she can leave her worries behind. She uses mocking humour to make bearable what is actually unbearable to her. She would have refused the interview, if her husband had not made the appointment.

*Recasting biography:* Of late, she is so overcome by thoughts of a terrible death and by loneliness that every new day she has to live brings her pain:

I am so tired of it. Every day in a wheelchair and in the evening, my legs hurt so badly. To me, it's terrible. I don't want to grow old this way... I don't want to think about it. Then I feel so lonesome that I do not want to wake up tomorrow. That is my only wish. That tomorrow morning I won't have to get up. With all my worries, I do not want to go on any more.

Mrs. Newcomb has not found new modes of living within her limitations. All salient aspects of self have been lost and no new worthwhile aspects have been discovered. The relationship with her husband has been disrupted but just once she would like to be able to tell him what's on her mind. Her only hope is that she can continue to put on a show of being happy, but there is no hope that times will get better. She sees absolutely no

direction to her life and her only escape from her suffocating fears is to die.

## Conclusion and discussion

This study offers insights into the way people with advanced MS accommodate to their illness. The body of data as a whole confirms MS as a physically exhausting disease with far-reaching psychosocial consequences for patients and family members alike. Our findings pertaining to the caregivers are explored elsewhere. The heavy demands placed on the biographical work of people with advanced MS can be explained by the fact that the illness touches upon all three concepts of the BBC and shatters the connection between them. It does so in an ongoing and severely damaging manner. A variety of examples of serious bodily failure and accompanying performance failures were reported. The loss of salient aspects of self was also illustrated. The empirical data presented here illustrate some of the general and already known features of progressive illnesses, and some of the more specific points that relate to MS. As bodily failure increases, performances have to be eliminated altogether and it appears in our data to be hard and sometimes even impossible to find new, fulfilling activities.

The downward phase of the illness trajectory itself sabotages successful accommodation as it constantly gives negative feedback on symptoms, performances and the implementation of biographical work. The ongoing deterioration sometimes leads people to give up their efforts altogether. In this phase, the hope and optimism that can pull people through in rough times, are not easy accessible in the form of medical treatment, for example. Hopes are limited to slowing down the illness course, maintaining certain salient bodily faculties and preventing admission to a nursing home.

Contextualizing the illness in terms of one's own biography varies from a state in which MS is not regarded a part of the biography, as in the case of Mrs. Newcomb, to a state in which MS is fused with one's identity. In most cases MS is a part of life, but does not determine all aspects of it. The case of Marc shows that, to a considerable extent, integration can give new meaning to the life course. It is possible to enjoy even the aspects of self which are related to illness, as Marc finds his contacts with fellow sufferers meaningful and enjoyable. But as Mr. Cunningham shows, the illness-related aspects can rule the patient's life without giving a new direction to it when they are not incorporated. The person is held captive by the disease and is led to a state of paralysis and retreat.

Coming to terms seems to be a necessary requirement for the processes of contextualization and reconstitution

to take place. When there is a considerable failure or refusal to accept the illness to some degree, as with Mr. Cunningham and Mrs. Newcomb, identity reconstitution fails. Both in their own way oppose the illness and have difficulty living in the present. This can be derived from the mottos according to which they live *I allow MS to take control over me* and *I have nothing to do with MS*. Others, such as Marc and Mrs. Ratcliff, have found a way to come to terms with their illness and are in one way or another satisfied with their altered performances. Their personal philosophies *I try to make the most of it* and *MS will never have the upper hand* are evidence of their will to go on.

There was a great deal of evidence in the transcripts that biographical recasting was an almost impossible task for the participants. The explanation lies in the absence of one of the essential conditions for this process, according to Corbin and Strauss (1988), which is having some degree of control over the illness trajectory. This is frustrated in MS because of the unpredictable course of the disease. The implications are significant, in that people with MS cannot give direction to their future biography or are unable to stop themselves from thinking about the worst option available, which in their eyes is institutionalization. Instead, people live one day at a time as much as possible although it makes them feel uncomfortable not to be able to plan for the future in terms of biography. Of course, our findings must be understood in relation to the selection of participants in a downward phase of MS. A life of dependency, whether bedridden or wheelchair bound, clearly offers fewer things to look forward to, even when the individual has accommodated rather well and looks on the bright side. This perhaps explains why our results do not match those of other studies which offered more positive results regarding adjustment to MS (e.g. Eklund & MacDonald, 1991; Stuijbergen & Rogers, 1997).

On the basis of other studies in this area which showed the large effects of chronic illness on the patients' identities, we chose Corbin and Strauss' framework of biographical work to analyse our data. Their framework proved to be useful, in the sense that it made us understand that people with MS are very much involved in processes that pertain to their whole being and to which they themselves refer as the all-embracing character of their illness. However, as Corbin and Strauss noted, the biographical processes are hard to disentangle empirically because they occur simultaneously and blend into each other. From that point of view, the central elements in the framework served as sensitizing concepts and guided our way of looking at and interpreting the data. Apart from trying to distinguish the different processes, the problem was resolved by focussing on case stories. The presentation of cases is one way to demonstrate in detail

the ensemble elements in each case and how these elements are configured to create a whole (Sandelowski, 1996).

The focus on the case stories also allowed us to depict developments in the accommodation to MS over a number of years, although this was not part of our research questions. Changes constitute small differences in biographical work or must be considered real turning points. Some patients have been able to remain in control of their lives so far and have only experienced some small setbacks. Others seem to have resigned themselves to the disease at an early stage, sometimes marked by the physician's formal diagnosis. Upheavals can bring about changes in the direction of more or less accommodation. Some were beaten by the disease at first, but gained control over it after some years. Others coped well with the disease until they found themselves caught up in it and lost courage. Break-throughs are always triggered by some event, whether this is the official diagnosis, a statement taken very seriously, the deterioration and death of other patients or the prospect of admission to an institution. More research into this topic is recommended because these triggers offer possibilities for intervening in the accommodation process as they set things in motion and can lead to major changes in a person's life course.

It would be an interesting issue for further study how the social context of people with MS influences their responses to MS. Our study has taken into account only a small part of the social and material factors and conditions and yet it provides some examples of drastic events with regard to employment, transport, housing and health services. Disability theorists have tried to bring it home that the way society is organized raises barriers for people with impairments (Barnes, Mercer, & Shakespeare, 1999). In terms of the accommodation process this implies that more concepts of self are lost as a consequence of the way society functions than would be necessary objectively when taking the physical consequences of MS into account. Nowadays, MS gives legitimate access to the 'impaired role' in Dutch and Belgium society. However, there are quite a few catches. At first, people who have constructed their concepts of self upon current appreciated values and expectations such as being active and self-sufficient, cannot change just like that to a different life even if it is justified by society (see also Charmaz, 1983). Secondly, even responses of disabled people are measured alongside the existing values as it is noticed that persons who are capable of 'living life to the max' despite their illness, can count on more respect and understanding than people who do not.

Since our study was aimed at the patients' accommodation in the present, we asked them to look at the present and in the light of this present to review their

past experiences and to think about their future plans. Because turning points and critical events stand out, interviewees were able to remember the significant changes reasonably accurately. Their stories were often confirmed by the family caregivers. There is a real possibility that the way they look at past experiences now is different from how they experienced them at that time. We consider the stories they told us to be the versions of their lives they were comfortable sharing with the interviewers at this specific moment in their lives (Holstein & Gubrium, 1995). With regard to the temporal perspective of accommodation, a longitudinal study with successive interviewing would be the designated method.

We deliberately chose to use a loosely structured interview style in which interviewees were invited to give their own accounts and to elaborate on the subjects they found important. Our participants did not see this as an invitation to only talk about the positive moments or successes, as we also gathered stories interlarded with grief, resentment, boredom and anger. Some authors warn interviewers not to be too understanding and open because this leads interviewees to provide only a positive self-presentation (Mazeland & Ten Have, 1996). Interviewers in their turn are seduced into probing interviewees for positive answers and trying to cheer them up (Houtkoop-Steenstra, 1997). In this study, the training and coaching given to interviewers probably prevented this from happening.

People with advanced MS are at risk of encountering major problems in terms of their sense of well being. Health care providers can use the information presented here to evaluate their decisions and actions carefully in the light of MS patients' difficulty in carrying out biographical work. Advising someone to use a device, such as a wheelchair or body lift, should not only be considered as a pragmatic, technical solution for failed body parts, but should also be seen as a development that has to be contextualized and accepted in the life course. The use of devices can open up the world to some people again while for others it can destroy a delicate equilibrium of self. Health professionals can support patients and their family members in moving beyond the present or learning to endure it.

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