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Milka Satinovic, Western Norway University, Norway

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Remodelling the Life Course: Making the Most of Life with Multiple Sclerosis

Milka Satinovic, Western Norway University, Norway

Abstract

The aim of the study was to develop a substantive grounded theory on how to live a life as good as possible with multiple sclerosis (MS). The question of how to improve the quality of life is of key importance when speaking of a chronic illness like MS. We still have little knowledge of this important question from the patients' perspective. Classic grounded theory was used to explore patients' experiences of living with MS. The aim was to identify their main concern and how they process this concern at different phases in their life course. Twenty-one interviews were conducted with 17 participants diagnosed with multiple sclerosis. Participant observation at five courses for people with a multiple sclerosis diagnosis generated field notes. The participants' main concern was how to live a life as good as possible in spite of their deteriorating health. The participants met this challenge through a process of remodelling the life course, in four phases: postponing (keeping up a normal life), adjusting (moving on to a changed life), restructuring (doing the best of it in a changed life), and transforming (preventing illness from controlling life). The remodelling process is influenced by the individual context, like the current health situation, biography, relations, and structural conditions. The process of remodelling helps us understand what facilitates and what hinders patients with MS from living a good life.

Keywords: multiple sclerosis, patient's perspective, quality of life, chronic illness, nursing, grounded theory.

Introduction

Multiple sclerosis (MS) is still an incurable and unpredictable chronic disease that is moderated by medication, and the persons' own lifelong balancing between the illness and life evolvment. MS is challenging for the persons living with MS and the health-care personnel (Maloni, 2013). For the person with MS the challenge is how to handle (manage) the unpredictable and lifelong bodily symptoms and changes, and at the same time try to live a life as good as possible within his or her own life context. For the health care personnel, the challenge is to understand the illness, the persons' own management strategies, rehabilitation, and health promotion in order to support and optimise the persons' potential to live a life as good as possible with MS (Ploughman et al., 2012).

In the study of factors, influencing healthy aging with MS (Ploughman et al., 2012) found resilience to be one of four fundamental factors "relating to the participants' abilities to adapt to changes and disease symptoms, seek out and gain new knowledge, pursue self-

therapy, deal with uncertainty, resolve problems on one's own and cope with and overcome barriers" (p. 29). Thus, understanding the subjective experience of people living as well as possible with multiple sclerosis (MS) is of core importance in nursing, medical treatment, rehabilitation, and health care planning.

Quantitative measurements of quality of life (QOL) have earlier indicated lower quality levels for people with MS diagnoses compared to those with other chronic illnesses (Benito-Leon, Manuel Morales, Rivera-Navarro, & Mitchell, 2003; McCabe & De Judicibus, 2005; Nortvedt & Riise, 2003). In contrast, a study of the relationship between QOL and coping was evaluated by McCabe, Stokes & McDonald, 2009). The study, which extended over a period of two years, revealed that people with MS increase their global quality of life over time. They experience higher psychological QOL, higher level of detachment, and are more focused on the positive coping than the general population. Studies on quality of life in MS using qualitative methods have focused (Dubouloz, King & Paterson 2010; Reynolds & Prior 2003; Russel, Mark & White 2006; Somerset, Sharp & Campbell. 2002) on psychosocial processes from the patient's perspective.

Studies by Thorne and Paterson (1998), Thorne and Paterson (2000) and Paterson (2003) showed that shifting between a health and an illness perspective is common when living with a chronic illness. Focusing on people with MS, Somerset, Sharp and Campbell (2003) showed that they experience themselves as reasonably happy when they can have an impact on the illness trajectory. Reynolds and Prior (2003) reported that the central challenge for women living with MS was how to accommodate the illness and maintain an acceptable way of life. Moreover, the patients experienced illness-related changes as an opportunity for growth and development.

Although not related to MS, Dubouloz, King, Paterson, Ashe, Chevie, and Moldoveanu (2010) described how people with diabetes and HIV go through a process of transformation by embracing the challenge, making adjustments, and integrating a new way of being, thereby generating opportunities for a good life. In this article, I elaborate a substantive grounded theory study on the process by which people with MS try to live a life as good as possible in spite of deterioration of illness.

Design and methodology

Classic grounded theory (Glaser & Strauss 1967; Glaser, 1978)) was applied to develop a substantive grounded theory on how to live a life as good as possible with an MS-diagnosis. The study was carried out in Western Norway, a high-risk area for MS (Author, 2009), in cooperation with the Multiple Sclerosis National Competence Centre.

Participants

The sample selected included a variety of factors: related to type of MS diagnosis, capabilities measured by Expanded Disability Status Scale (EDSS), duration of illness, and gender. The participants were 18 years or older and without a psychiatric diagnosis.

Ethical approval

The Regional Ethical Committee for Medical Research approved the study. All participants were informed that participation was voluntary and they were guaranteed anonymity and confidentiality. Written consent was obtained.

Data collection and analysis

Data collection and data analysis ran parallel during the two main phases. Twenty-one interviews with 17 participants diagnosed with MS were conducted in two phases by the author.

In phase one in 2000-2001, 13 interviews were carried out with 10 participants. As the incidents were coded and compared, they gave rise to new concepts and were renamed if necessary. Memos were written parallel with the coding. The analysis was characterized by constantly comparing, modifying, and renaming—not only the concepts and categories but also what was thought to be a core variable. Two other researchers also took part in the concept-development process in discussing and clarifying the new developed concepts.

Phase two, 2002-2004 in data collection process was guided by theoretical sampling, and took place until data saturation was obtained. It consisted of eight new interviews and participant observations at five courses for MS-patients.

Criteria for evaluation of a developed grounded theory

In this study, the criteria (Glaser, 1978) for fit, relevance and workability have been ensured through data collection and analysis: by constantly comparing incidents to incident and theoretical sampling (fit), by identifying main concern (relevance) and conceptualizing the pattern for handling the main concern (workability). It was further ensured by describing how the pattern of action varies with the life context of the person. With the regard to modifiability, developed concepts were altered in the light of new data through constant comparison.

The substantive grounded theory of remodelling the life course

The participants' main concern was how to live a life as good as possible in spite of the deterioration of their health. The participants met this challenge through a process of remodelling the life course—the core category in this study and explains how they solved their main concern.

Remodelling the life course has four phases: postponing, adjusting, restructuring, and transforming with distinct cutting points. However, a person can move between phases as the life context of the person changes. Four significant conditions were identified: present health situation, biography, relations, and structural conditions.

The process of life course remodelling seems to be a driving force in achieving a good life with MS. When remodelling is difficult or impossible to achieve, suffering and even suicidal thoughts can dominate.

Postponing

In the first phase of the remodelling process, participants tried to achieve a good life by maintaining their previous life course and postponing remodelling process. Their concept of life with MS can be expressed like, "I have MS and I will try to live a normal life for as long as possible". The postponing strategies are concealing, distancing and comparing with others.

Concealing is normally used when the illness is invisible. It is selective and application varies within different contact levels and relations such as family members, employers, neighbours, and society at large. Patients may tell people they are well-aware of the truth and conceal it from the everyone else.

Distancing is expressed in the hope that the diagnosis is not correct by ignoring and not talking about MS, and keeping all MS-related issues at a distance. According to one participant, "When I got the MS diagnosis, those two letters did not count to me. . . . I got a new job . . . and I enjoyed the job". Contacting other persons with MS and attending meetings in MS societies were seen as a threat to their identity as a healthy and active person. Distancing seems to allow patients time to understand life with MS and to move towards the next phase.

The third strategy which helps patients to keep up the previous life course and postpone remodelling is comparing themselves with others, both healthy people and people with serious MS. The fact that life is hard and sometimes full of challenges helps them to endure their one's own fear, and inadequacy. According to one participant, "It's hard to work full time, to have a family and children Other people complain too." This participant with invisible MS, uses a comparison strategy to hold on to her "normal" life as long as possible. Another participant considered herself lucky, compared to others who experienced worsening in the illness, and who may be suffering from constant pain.

The postponing of the remodelling process may be maintained as long as the illness is invisible to others. Hence, the consequences of postponing strategies are experienced as positive. When the patients' state of health deteriorates, they will be compelled to be open about the illness, and will start to adjust to the fact that MS influences life considerably. A transition to a new phase will take place.

Adjusting

The second phase of the remodelling process is adjusting; it appears if the illness suddenly becomes visible and the person may be forced to disclose the illness. In other situations, the transition to a new phase moves slowly as a person comes to understand that postponing strategies take most of one's energy, and leave little for enjoyment of life. The problem is no longer how to maintain a normal life but what has to be changed in life, how and when it can be done, and what consequences it will have for the enjoyment of life. The strategies that are used to adjust life course are: accepting the need for changes, developing competence to handle MS-related problems and balancing between illness issues and life enjoyment.

Accepting the changes and the fact that the illness is a part of life seems to be crucial to the process of remodelling a person's life course. If the persons cannot accept the illness and MS related changes, they will always long for their earlier life. This position will hinder them in dealing with the illness and establishing a good life in their new circumstances. A chronic illness like MS affects nearly all aspects of life in physical,

psychosocial and existential ways. Some of the complexity of remodelling a life course is evident in one participant's comment: "You lose so much . . ., but you can also gain new values by looking at life in a different way . . . from a different perspective."

Accepting the changes caused by the illness is not enough, however. Relations at home, at work, and in society also affect the process. Friends and workmates may have a problem realizing what it really means to live with MS even though they accept it as a fact. The problem of fatigue can be difficult to grasp and other people's attitudes towards MS can hinder the personal process of acceptance.

Developing one's own competence includes knowledge, attitudes, and skills to cope with various MS-related problems in various life domains. It may, for example, be important to develop skills to administer medication, self-catheterisation and to get a wheelchair or a car. However, at the same time one also has to change his or her attitude towards such activities. The change implies a shift from seeing the wheelchair as the worst scenario to seeing it as a useful means to gain control and be mobile. Competence develops through learning by one's own experience, pieces of advice from health personnel, or from other people with MS. Sources like classes on MS, rehabilitation, and printed material are also important. Furthermore, competence depends on knowledge of one's personal limits and how many activities one can handle. One participant describes the process in this way: "Nobody can take care of your life during the day; it's only you who can do it. You can ask for advice . . . but you have to do it yourself."

Developing competence is a complex and difficult process which takes time and energy and implies a lot of interaction with health-care personnel, relatives, other people with MS, and people in general. These interactions may prohibit and promote the process of acquiring competence.

As the illness becomes accepted as a part of life, and the person's capability to handle MS-related problems improves, the focus changes to a balancing process. To balance between illness issues and life enjoyment is a key challenge. To start using a wheelchair or making a conscious choice concerning work or disablement at the right time—not too early or not too late—is important. The right decision for the individual will vary depending on the illness type and severity, personal values, and life history, on one hand, and on structural conditions and his or her welfare situation on the other. A large number of persons at different community offices, and only limited possibilities to choose between job or disability pension, may make a process of change difficult to achieve in a satisfying way. Taboo about the diagnosis in society in general may also hinder or delay a person in accepting the illness and developing his or her capabilities to tackle illness-related problems and issues.

The consequences of change in the course of life are sometimes positive, negative, and ambiguous. The positive consequences are described as improved relations with a spouse, in the neighbourhood, or at work provided that there is openness, knowledge, and understanding about the illness. Openness can also clear the way for relations with people with invisible MS. During the process of change, people can experience growth and development. The statement "You have been forced to make up your mind on what to get out of your life" describes the positive aspect of change even if one were forced to it. The challenges are no longer experienced only as a threat but also as a possibility. Participants described that they had thought using a wheelchair or doing

self-catheterization were the worst things they could do. After they had started using these devices, they saw them as possibilities to decide when to go to the toilet and expend more energy to do something they liked instead of walking with crutches.

As a person develops competence to manage everyday life with MS, and the MS is in a stable phase, he or she can gradually seem to shift the focus from problems to possibilities.

Restructuring

In this phase, the illness is considered as a normal part of life; it is important to make the best of the situation by restructuring the life course. The concept of life with MS can be described as: "I have MS but I try to get the best possible out of it".

The restructuring is about how to make the best of it and the importance of focusing on life as a whole and not only on the parts of it, related to illness. One of the participants put it like this:

I am ill. I have always thought I have MS. But I don't go around as a sick person all the time. I am ill when I have a flu or bowel infection . . . I have played down the illness.

Instead of using all energy on illness, one can now use it on life involvement. Strategies that are applied during this phase are: focusing on values, searching for alternative activities, focusing on community, and using humour.

The strategy of focusing on values is characterized by searching for valuable experience in the past, the present and the future. Appreciation of the past helps to live in the present. Being a father or having grandchildren will draw attention from illness to more pleasant elements of life.

Life enjoyment is an important value for some people. They can choose between strictly following diet recommendations, or making variations so they could enjoy life, with no bad conscience and fear of deterioration of health. Another participant describes how her energy rose so that she could stand up from the wheelchair at midnight after spending the evening and having fun with her friends in a MS-group. These examples show that doing desired activities generates joy and energy.

To many people, doing sports and outdoor activities is important. Such activities may be impossible to perform because of fatigue, problems with balancing, and spasticity. Therefore, people search to find alternatives that can bring them in contact with nature. "I can't walk that much but I can cycle in the woods" is one example of alternative ways. If one lives on disability pension, it is important not to stay at home all day. Meeting other people for coffee, shopping, going to the cinema or just enjoying nature brings joy to life.

Focusing on possibilities has to do with social activities and doing things with other people. Instead of having focus on their own situation, persons with MS look at community and fellowship. One can be a person who invites neighbours or relatives for a cup of coffee or goes to the theatre. To join an association of interest for people with MS may become a possibility in this phase. In the early phases, one would not take that into consideration. Attending an MS association is now considered as an opportunity to get information about MS, to meet others with MS regularly, to join common vacation trips and so on.

Use of humour is a strategy that can be used to turn negative experiences, feelings, and events into positive ones. Humour seems to be an effective way to create a relaxed atmosphere. Having a memory problem can be turned around to something with a positive aspect also. One participant started to learn a foreign language and had a positive attitude about it, even if she forgot some of it quite soon. She saw it as an opportunity to test her capability and laughed when she did not manage. Not having a job may be seen with a positive or humoristic attitude, for example "You are lucky not having to get up early in the morning and have the opportunity to use your time as you wish".

Restructuring the course of life by focusing on possibilities and making the best of it has a lot of positive consequences described as joy of life, zest of life, and courage. The joy of doing something one wants to do, being active with something meaningful, or just being happy in the company of others are some of the ways participants describe a good life. Sharing memories and pieces of experience with others, being open to support from other people in a situation of distress, or being appreciative of relatives or friends for being there to help, laugh, and joke at different illness related problems can increase joy of life and feelings of fellowship.

Ambiguous consequences of restructuring are sometimes also described as a failure in relational or structural factors. If one has been given the opportunity to work with something meaningful for a while and this activity cannot be continued because of a job shortage, one can be disappointed. If one has met the person with whom one wants to build a future and fails, the trust in other people can be weakened; it takes time to restore *it*.

Negative consequences are experienced when one has come into a vicious circle with health care personnel and feels that the need for help to restructure is not understood. Long waiting hours and shortage of flexibility in different helping instances can result in a feeling of helplessness. As we see, the surroundings can contribute in a positive or negative way when a person with MS tries to make the best of it and live a good life with MS.

Transforming

When the illness gets worse—acutely in a clinical relapse or through a steady progression—the person will again experience a challenge to keep the illness from controlling his or her life, and a shift to the next phase will take place. The transformation strategies have been identified when health worsens and fear of the future increases: Seeking a respite from the illness, being positive, hoping, and not giving in.

There are different ways to seek respite from the illness. One can be occupied with other activities; one can socialize with other people with MS in self-help groups; or one can seek help in different health care institutions like rehabilitation, MS courses, etc.

Participation in a self-help group may function as a type of safety valve for the individual. The group is the place where one can behave in a natural way, forget the illness, and vent frustration. Being at a rehabilitation unit can do "miracles". Staying in a rehabilitation unit can help the person to feel free and give a temporary respite from the illness, and simultaneously help the person start to manage some of the problems

accumulated in the wake of illness. "It was health care personnel who got going the application for the car . . . they push you and guide you how to proceed . . ." Getting free from everyday activities like housework, cooking etc. gives a necessary physical rest. A rehabilitation stay can involve family or other help units in problem solving and engagement. Last but not least, they can all get updated knowledge about the illness, medication, treatment possibilities, etc.

Another strategy used to hinder the illness from controlling life is hoping for the best. Hoping that something will happen that can improve the health situation seems to be central. Some examples may illustrate the use of this strategy. One participant said that she was able to stand the grave deterioration of her health because she always hoped that the good days will return. This was the case even if friends and family imagined that they probably couldn't deal with such a situation themselves. But it's not always easy to keep up hope, and repeated fits of deterioration can challenge even the most optimistic person. When the person succeeds to hinder illness in controlling life, he or she can carry on the fight.

The strategy that can promote hope is being positive. Working on how to tackle difficult situations can help a person develop a positive stance. Such work can be very difficult for persons with a pessimistic point of view or when they are deeply depressed. However, the difficult life situation can also bring a person to an existential decision about what he or she wants to get out of life. Low energy, fatigue, pain, and no signs of progress may lead to a point of no return: to live or die. Even if it's difficult to be optimistic in a situation when life is at stake, this kind of experience may give life a new chance. As one participant told "I decided I want to live. . .". After his decision, he got help to overcome his feeling of helplessness even if he was close to giving up. If one succeeds in keeping the illness from controlling his or her whole life, a shift of focusing on the possibilities may again occur.

Discussion

Remodelling the life course represents a conceptualization of the main concern: how to live a life as good as possible with unpredictable conditions like MS, and patterns for how to manage this concern. Remodelling the life course is a basic psychosocial process used by persons living with different types of MS. It has four phases: postponing, adjusting, restructuring, and transforming with distinct cutting points. However, a person can move between the phases as the life context of the person changes. The process is ongoing but can come to a standstill if the illness is mild and invisible to others. The balancing between MS issues and life involvement occupies a central position in the remodelling process as long as the illness is stable. As health deteriorates, the transforming phase is used in order to make the most of life with MS.

Four significant conditions that affect remodelling the life course were identified: the present health situation, life history, relations, and structural conditions. These conditions provide an understanding of factors that may prohibit or facilitate remodelling the process. It is important to support the person during the remodelling process and to take into consideration his or her choices and autonomy. Thus, the next of kin, health care personnel, and the society at large can make a difference to promote a life that is as good as possible with MS.

The remodelling process is in line with the shifting perspectives model (Paterson, 2003; Thorne & Paterson, 1998) that describes life with chronic illness as a continually shifting process between a wellness-in-foreground and the illness-in-foreground perspective (Paterson, 2003). In the remodelling process, the illness and the wellness perspective run more or less parallel. MS patients have to take both into consideration in order to live a life as good as possible as they care for the illness issues.

The remodelling process is also in line with the transformation model (Dubouloz et al., 2010), which describes life with chronic illness like HIV and diabetes through three phases: initial response, embracing the challenge, and integrating new ways of being. The remodelling process differs from the transformation model by having four phases, mostly because of an unpredictable and uncertain illness trajectory.

Topcu Buchanan, Aubeeluck & Garip. (2016) have studied the experience of the next of kin of persons with MS and found that formal support from health professionals helped the patients' next of kin care for their loved ones. Some next of kin also report how they struggle to maintain normality in a family with a person with MS (Topcu et al., 2016). Maintaining normality is central for persons with MS as well and is consistent with the findings of Topcu et al. (2016).

Mikula et al. (2013) have studied coping and quality of life in patients with MS and report that strategies on "stopping negative emotions seems to be very adaptive for patients with MS" (p.732) and that the use of these strategies explained the most of the variance of all the coping strategies (Mikula et al., 2013). The part of the remodelling process with its strategies like concealing, distancing, being positive, hoping, and not giving in, is consistent with the findings of Mikula et al.

The need for respite in life with chronic illness has been explored by Årestedt, Benzein, Persson & Rämgård (2016). They found that three places for respite (a place for relief, a place for reflection, and place for recreation) are important for families living with chronic illness. Remodelling the life course also shows that seeking respite is an important strategy for persons with MS as well, and is especially recognizable in the transforming phase.

Audulv (2016) identified four patterns of self-management in life with chronic illnesses over time: consistent (taking medications), episodic (doing exercise), on demand (managing acute episodes), and transitional (adaptation of work and household activities). In the process of remodelling the life course, all of these four patterns are recognizable and support the developed remodelling concept in this study.

The concept remodelling the life course explains how persons with MS handled their main concern: how to live a life as good as possible. Different phases of the process are consistent directly or indirectly with the above studies in the same substantive area.

Limitations of the study

The study has been carried out with persons who more or less have succeeded with their remodelling process. A fewer number of participants did not succeed in the remodelling process. It would therefore be desirable to study the context and the experience of

remodelling the life course in people who do not succeed in living a life as good as possible with MS.

A new data collection would also benefit in order to check out the need for modification of the developed substantive grounded theory. We know that the process of diagnosis and treatment has changed with new technology. A diagnosis can now be established more quickly, and the treatment and the person's remodelling work may profit. It would also be desirable to study the concept of remodelling life course in the context of other chronic illnesses and thus develop a formal grounded theory.

Implications for practice

The concept of remodelling the course of life can be of great help for health care personnel as well as for patients in understanding what's going on in a person's life with MS, which strategies are used, how they vary, and what consequences they can bring for a good life for the individual.

These concepts can be used for screening of persons with MS during a dialog with a nurse in order to get an impression of the phase in which the patient finds himself or herself. Furthermore, they can be used in developing a program for people with MS in order to support, empower, and prepare patients to manage their own health and generate a good life with MS. The theory can further on be explored for applicability to patients with chronic fatigue syndrome.

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