Expressions of Freedom in Everyday Life: The Meaning of Women’s Experiences of Living with Multiple Sclerosis

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To my family
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ABSTRACT
The aim of this licentiate thesis was to describe the meaning of women’s experiences of living with multiple sclerosis (MS). It focuses specifically on the women’s experiences of daily life (I) and the experience of fatigue (II). Narrative interviews were conducted with ten women living with MS and the interviews were analyzed with a phenomenological hermeneutic interpretation. This licentiate thesis proposes that the meaning of living with MS for women can be seen as living an everyday life of restrained freedom being defined by the compulsions of the body, and in the same time a feat for freedom in everyday life exists. The constraints of freedom in everyday life involve the body, relations to others, and the inability of being involved in everyday life in a desired way. Despite the demands of the failing body the women with MS choose to involve themselves in everyday life rather than withdraw. While their experience of freedom is deterred, these women seem to feat for an inner freedom, which is used to approach life and meet the demands of illness. The relationship between this inner freedom and the restrained freedom means a feat for freedom in order to meet the conditions that MS brings into the women’s everyday life.

Key words: lived experience, women, multiple sclerosis, fatigue, phenomenological hermeneutics, body, dignity, freedom, nursing
ORIGINAL PAPERS
This licentiate thesis is based on the following papers, which will be referred to in the text by their Roman numerals:


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INTRODUCTION

People living with multiple sclerosis (MS) have described the unpredictability of the illness and the experience of fatigue to be the most difficult problems to face. Multiple sclerosis is most common among women and research shows that women find it hard to convince others about their individual needs. Since research concerning women’s experiences of living with MS is limited, this licentiate thesis focuses on women’s experiences of living with MS.

Theoretical foundation

In this licentiate thesis phenomenological hermeneutics is used within the paradigm of nursing. The focus of nursing science is the person and the individual experiences concerning life situations, illness, perspectives of life, and also beliefs in everyday life. The goal of research in the nursing paradigm is first and foremost to strengthen the sense of dignity and to support the well-being and health of people in their everyday life (Eriksson, 2002; Lavoie, De Koninck & Blondeau, 2006).

Phenomenological research sets goals for achieving a deepened understanding of the meaning of everyday experiences. The life world, in this view, is central to human understanding and according to Husserl (2004) the life world or everyday life is characterized by a taken-for-grantedness and pre-reflective assumptions. In a phenomenological attitude, questions are raised against this taken-for-grantedness, and the essential meaning of a phenomenon can thus be revealed. According to Dahlberg and Dahlberg (2004), the phenomenology of Husserl, concerning the human conscience and the world, develops with Merleau-Ponty’s phenomenology of the body. Merleau-Ponty (1996) found that the body is a person’s first and foremost access to the world. In this view the body embodies unity and wholeness in experiencing oneself in the world. A person does not own or possess a body, but in actuality exists in his or her body, thereby, experiences life as lived through the body (Merleau-Ponty, 1997). The aim of phenomenology according to Merleau-Ponty (1996), is not to provide causal explanations but to describe lived experiences. In the view of Ricoeur (1998) phenomenology and hermeneutics are each other’s prerequisites. Further, phenomenology, according to Ricoeur, needs to be interpretative and therefore, hermeneutics and phenomenology correspond as both focus on meaning. Phenomenology can be understood as explaining, making lived experience explicit, while hermeneutics can be understood as text-oriented interpretation (Ricoeur, 1976, 1998). Together, phenomenological hermeneutics connotes an understanding of the meaning of a phenomenon through critical discussion.
(cf. Ricoeur, 1976, 1998). According to Kristensson Uggl (1999) Ricoeur presumed that people are always interpretative and open to the world and communication with others is fundamental in gaining knowledge. Within nursing, the view of an interacting and interpreting person who gives meaning to his or her experiences is imposed (Wiklund, Lindholm & Lindström, 2002). Lindseth and Norberg (2004) describe phenomenological hermeneutic interpretation as fruitful when it comes to understanding the meaning that people give to their experiences.

Experiences of living with chronic illness
Throughout life, people in general are faced with constant change. Living with a chronic illness often involves confrontations with unexpected and unwanted occurrences. Countering the demands of an illness and its consequences for people often implies lifestyle changes (Charmaz, 2002, 2006; Michael, 1996). Chronic illness has been shown by Sexton and Munro (1988) and Öhman, Söderberg and Lundman (2003) to restrict people in their everyday lives, which causes experiences of loneliness and feelings of being excluded from living in a community with others. Charmaz (2006) showed that people with chronic illness are faced with the paradox of being in a system where the individual responsibility for health is maximized, but the support facilities for individuals are minimized. When the body is failing due to illness, the very foundation of a person’s existence is wounded and if care is not focused on supporting that primary basis, illness eventually can destroy the confidence of the person (Corbin & Strauss, 1987). Despite the demands that are imposed by a chronic illness, studies (e.g., Jumisko, Lexell & Söderberg, 2005; King et al., 2003; Söderberg, Lundman & Norberg, 1999; Öhman et al., 2003) show that people with chronic illness distinctly express feelings of meaningfulness and demonstrate determined struggle in their everyday lives. Several studies (Corbin & Strauss, 1987; Kralik, Koch, Price & Howard, 2004; Charmaz, 2006) pointed out that people find new ways of learning to live with the illness, when the changes that are brought forward by illness can be included in life and identity.

Multiple sclerosis
Multiple sclerosis is a chronic inflammatory disease of the central nervous system (CNS) with a course that varies and a prognosis that is uncertain (Schapiro, 2001; Vukusic & Confavreux, 2001). The aetiology of MS is still unclear, but studies indicate that genetic, immunological and environmental factors are important (Soldan & Jacobson, 2001). Multiple sclerosis usually begins between 20 and 40 years of age and is next to accidents the most common neurological
disability among young adults. Minden, Marder, Harrold and Dor (1993) showed that 73 percent of people living with MS are women, and Flachenecker (2006) revealed that women are at least twice as often affected than men. Multiple sclerosis is also more frequent among Caucasians, and ethnic factors are of significance. Northern Europe, North America, Australia, and New Zealand have the highest prevalence of the disease, however ethnic populations in these areas seem resistant (Flachenecker, 2006).

The symptoms of MS vary and are dependent on the site of inflammation in the CNS. The most common symptoms are numbness, visual impairment, lack of coordination, paralysis, fatigue, sphincter dysfunction and sexual problems (Schapiro, 2001; Vukusic & Confavreux, 2001). The clinical courses that have been defined are of three types, relapsing-remitting MS, primary-progressive MS and secondary-progressive MS. The relapsing-remitting type of MS occurs in 85-90 percent of the afflicted persons and is characterized by episodes of neurological deterioration, which evolves and recovers. The primary-progressive MS is the most uncommon of the three types and occurs in 5-10 percent of persons with a steady decline of neurological function. The secondary-progressive type of MS occurs after 10-15 years among up to 50 percent of persons living with MS, and the phase is characterized by steady progression (Weinshenker et al., 1989). The diagnosis of MS is made from a combination of clinical history, physical examination, laboratory tests and magnetic resonance imaging (MRI) that has become predominant to establish a clear diagnosis (Polman, Reingold & Edan, 2005). Until today there is no known cure for MS, thus, treatment is focused on immune modulation with beta-interferon and symptom management (Flensner & Lindencrona, 2002; Hemmer, Nessler, Zhou, Kriscier & Hartung, 2006; Miller, 1997; Miller & Jezewski, 2001; Olsson, Piehl, Swanberg & Lidman, 2005; Pozzilli, Sbardella, De Giglio & Tomassini, 2006; Schapiro, 2001).

**Experiences of living with multiple sclerosis**

Multiple sclerosis considerably changes people’s everyday life and the power or capacity to meet personal expectations and, without doubt, others’ expectations too (Toombs, 1992; Yorkston, Klasner & Swanson, 2001). Toombs (1995) stated that living with MS implies insecurity on a daily basis, not knowing how long the body will retain its strength. For people living with MS, one’s own body is experienced as an obvious threat, and can no longer be taken for granted and trusted, instead, it demands constant attention. Courts, Buchanan and Werstlein (2004) stated that people with MS experience a period of suffering before diagnosis,
as their illness is not comprehended by others and they are liable to be branded as hypochondriacs by health care personnel. After diagnosis, people with MS describe a constant struggle to maintain an everyday life, which despite illness resembles life as when healthy. People with MS have expressed feelings of not being listened to and fighting against the illness alone. To manage the everyday life, people with MS find it urgent to prioritize their personal goals. The search for information and knowledge about the illness has been described as crucial, due to viewing knowledge as a way to maintain control (Courts et al., 2004; Isaksson & Ahlström, 2006; Miller & Jezewski, 2001). People with MS have far-reaching contacts with the health care and they search for support in order to manage the affects of illness in daily life. Studies (e.g., Courts et al., 2004; Koopman & Schweitzer, 1999; Miller, 1997; Toombs, 1992) highlight that people with MS describes problems in their interaction with health care personnel, this since, the symptoms of the illness strongly vary. People with MS also describe experiencing that symptoms are wrongly diagnosed, and emotional needs are being ignored. Bloom et al. (2006) showed that the expectations and goals of persons with MS and the goals of the clinical MS-team do not necessarily correspond with each other.

Living with MS often implies that possibilities to maintain interests and keeping contact with others that used to be an important part of life are restricted. Holland and Madonna (2005) showed that the illness affects people’s self-esteem, family relations, and their relations with friends and others. Being able to participate in a context with others and to maintain social networks require power and energy, which people with MS often lack (Flensner, Ek & Söderhamn, 2003; Leino-Kilpi, Luoto & Katajisto, 1998). Nicholl, Lincoln, Francis and Stephan (2001) revealed that people with MS experienced lower life quality than people living with other chronic illnesses, and this had an obvious connection with the loss of energy that people with MS experience and also the restricted possibilities of being in a fellowship with others. Further, Gottberg et al. (2006) showed that the quality of life for people with MS is affected by the severity of the disease and the course of its progression. Barnwell and Kavanagh (1997) stated that maintaining contacts with others and the possibilities of being a part of society is of vital importance when it comes to being able to live with MS. Studies (Barton, Magilvy & Quinn, 1994; Miller, 1997; Toombs, 1995) show that people with MS experience the unpredictability of the illness and the loss of control in everyday life as the most trouble some problem. Despite this, living with MS involves a hope for becoming free from limitations.
Multiple sclerosis is most common among women and it has been shown that women with MS lose out on several aspects of life in their struggle against the compulsions of this illness. These changes involve a movement away, from being healthy and active, leading a fulfilling private life, and being engaged in a career, to becoming dependent on others in several ways (Koch & Kelly, 1999a). Koch, Kralik and Eastwood (2002) showed that women with MS often feel betrayed by their own bodies which no longer officiate as before. Problems connected with incontinence are described and women with MS find it a painful and humiliating experience to need assistance with the most fundamental needs (Koch & Kelly, 1999b). Women with MS also reveal that it takes time to understand and get to know the changed body in order to live with the illness (Kralik, Koch & Eastwood, 2003). Managing everyday life can be hard when unpredictability and lack of control is a part of the everyday life existence (Dyck, 1995; Koch et al., 2002). Crigger (1996) described that women with MS valued relations and contacts with others, and considered this to be the most important factor to retain their self esteem and well being. Moreover, Crigger stated that women with MS expected support in order to manage the unpredictability of the illness and desired to preserve and develop communions with others. Support from others and stability in relationship or marriage, and the ability to continue working were factors that helped mitigate the women’s feelings of being restricted (Clingerman, Stuifbergen & Becker, 2004).

Reynolds and Prior (2003) stated that women living with MS constantly negotiate between negative and positive forces competing for power in their efforts to achieve a quality life. Insecurity, discrimination, problems in getting access to public places, and financial difficulties were a source of a constant struggle for them. Despite these factors of hindrance, they strive for quality in life (Dyck, 1995; Reynolds & Prior, 2003). Focusing on personal goals, maintaining roles of value, trying different life styles to keep alive earlier interests, and maintaining relationships were viewed as a positive way to experience wellbeing. Despite this, feelings of frustration, anger, and grief were often present as the body does not work as it should, and also because these women are not able to participate effectively in communion with others (Dyck, 1995; Reynolds & Prior, 2003). Koch and Kelly (1999b) described that women with MS, in their contacts with health care personnel, often felt that they lack knowledge about their individual situation and needs. Abma, Oesburg, Widdershoven, Goldsteen and Verkerk (2005) showed that women with MS lack recognition of their vulnerability and there was deficient space for expressing feelings of grief and powerlessness when meeting health care personnel.
Experiences of fatigue in multiple sclerosis

Fatigue is a common experience among people with MS (Bakshi et al., 2000; Krupp et al., 1995; Krupp, 2003, 2006; Stuifbergen & Rogers, 1997). Studies (e.g., Krupp, Alvarez, La Rocca & Scheinberg, 1988; Schapiro, 2001) have shown that 78-87 percent of persons living with MS experience fatigue. The etiology is still not known in detail (Krupp & Polina, 1996; Krupp, 2003; Bakshi et al., 2000) but there are no doubts that fatigue has a strong impact on people’s lives (Bakshi et al., 2000; Isaksson, Ahlström & Gunnarsson, 2005; Stuifbergen & Rogers, 1997). According to Toombs (1995), fatigue in MS is an invisible and misunderstood symptom and Nordeson (1998), showed that people with MS constantly fight against fatigue. According to Krupp et al. (1988), fatigue in MS is worsened by heat, and this fatigue strongly differs from the transient tiredness that healthy people feel. Studies (Flensner et al., 2003; Stuifbergen & Rogers, 1997) show that for a person with MS, the experience of fatigue is very different from the tiredness they felt when they were healthy. Fatigue as documented in relation to MS has similarities with many chronic illnesses like cancer (Krishnasamy, 2000), chronic obstructive airway disease (Ream & Richardson, 1997), HIV- infection (Rose, Pugh, Lears & Gordon, 1998), hepatitis C (Glacken, Coates, Kernohan & Hegarty, 2003), and fibromyalgia (Söderberg, Lundman & Norberg, 2002).

Fatigue in MS was described by Toombs (1995) as follows: 'exhaustion means sitting in a chair and being literally unable to move’ (p. 9). According to Stuifbergen and Rogers (1997), people with MS describe fatigue as a paralyzing force obviously and constantly present. The cognitive ability among people with MS has also been reported to be influenced by fatigue (Krupp & Elkins, 2000) and this undermines the quality of life (Fisk, Pontefract, Ritvo, Archibald & Murray, 1994; Janardhan & Bakshi, 2002; Miller, 2003). Krupp et al. (1988) show that the experience of fatigue among persons with MS is not related to objective physical symptoms or neurological deteriorations. Fatigue related to MS is a time-consuming phenomenon, which affects the whole person (Flensner et al., 2003). Ward and Winters (2003) described it as an overwhelming feeling of bodily exhaustion which consumes the person’s life. Fatigue and energy loss are reasons why people with MS cannot work full time (Black, Grant, Lapsley & Rawson, 1994; Jongbloed, 1998; Kinkel, 2000).
RATIONALE

To summarize, the literature review shows that the field of research about MS is quite extensive and it is obvious that MS affects and considerably changes people’s lives. The symptoms of the illness and factors like people’s inabilities, abilities of adjustment, coping, social support, and self-assistance are areas that have been explored. Research about fatigue in MS is predominantly quantitative. Fatigue is described as an invisible and misunderstood phenomenon without relation to objective physical symptoms, which increase the risk of that expectations of people with MS are not being met. The literature review reveals a lack of knowledge concerning the meaning of living with MS for women, with the focus of daily life and the experience of fatigue. This study will provide knowledge in these areas, and this kind of knowledge will give applications to improve care and nursing in a manner that is congruent with the expectations and needs of women with MS. Care and nursing that corresponds to the women’s expectations and needs gives necessary conditions to develop support that increases wellbeing and health among women with MS.

THE AIM OF THE LICENTIATE THESIS

The aim of this licentiate thesis was to describe the meaning of women’s experiences of living with multiple sclerosis. It focuses specifically on the women’s experiences of daily life (I) and the experience of fatigue (II).

METHODS

Participants, procedure and context

Ten women diagnosed with secondary progressive MS participated in the study (I, II). The sample was purposive and the criteria of participation were; adult women, living with the secondary progressive type of MS with documented MS-related fatigue and the fact that their everyday lives were influenced by MS. The women’s age ranged from 43-59 years (md: 49) and they had experienced symptoms in about 9-39 years (md: 23). The time lapse since diagnosis varied from 5-29 years (md: 18. 5). Nine women were married and one woman was cohabiting. Eight women were receiving disability pension and two of the women were working part-time. All the women were in need of mobility aids. The women’s participation was arranged through a rehabilitation hospital in the south of Sweden. At the rehabilitation hospital the coordinator of the MS-team contacted the women and informed them about the nature of the study and also invited them to participate. After acceptance of further contact, each woman was contacted by telephone to arrange an interview.
**Interviews**

The interviews with the women with MS were conducted in 2002. Since the purpose of the interviews presented in Paper I and II was to describe the meaning of women’s experiences of living with MS, personal audiotaped interviews were conducted using a narrative approach (cf. Mishler, 1986; Sandelowski, 1991). Narrative interviewing provides possibilities to gain understanding of how people express their experience of a certain phenomenon and what that phenomenon means to a person in daily life (Mishler, 1986). According to Sandelowski (1991) narratives show how persons construct past and future life events in order to describe their experience. The women were asked to talk about their daily lives with MS, their experiences of symptoms, thoughts about their illness, their relationships with others, and their experience of fatigue in daily life. When needed, questions were asked to clarify their experiences, e.g., would you like to explain further, how did you feel then, can you give an example. Seven women wanted to be interviewed in their home and three women preferred being interviewed in a quiet and separated room at the rehabilitation clinic. The interviews lasted between 40-60 minutes. The narratives were later transcribed verbatim.

**The phenomenological hermeneutical interpretation**

In order to analyze the transcribed interviews (I, II) the method of phenomenological hermeneutic interpretation described by Lindseth and Norberg (2004) and inspired by the philosophy of Ricoeur (1976) was used. Using this method of research attempts are made to explain and from there understand the meaning of a phenomenon by interpretation of narratives fixed as text. To gain understanding a constant movement between the text as a whole and also its parts are a necessity. Moreover according to Ricoeur, the lived experience of a person always remains private but its meaning can be described to others. Through text interpretation of lived experience a deeper understanding of the phenomenon can be gained through a dialectic movement between understanding and explanation, with the aim to reach a new comprehensive understanding. In order to do so, the text must be viewed as mute. Because of the absence of the author, the reader is left to interpret the text in a cumulative holistic process whereby the text is viewed from plural sides. The reader can never view all sides of the text at once, therefore, the process of interpretation needs to be cumulative and holistic, moving between the parts and the whole.

Using phenomenological hermeneutic interpretation as method, interpretation is conducted through three interrelated phases. Interpretation starts with a naïve reading of the text in order
to gain a sense of the whole. This provides ideas for the structural analysis, which is characterized by dividing the text into meaning units linked to each other by content. Based on similarities and differences the meaning units are then organized into subthemes and themes, with the aim of explaining the text. Developed by and supported from the naïve reading, the structural analysis, the pre-understanding of the authors, and the literature, the text was interpreted in its whole with the result of a new comprehensive understanding (Lindseth & Norberg, 2004). In this licentiate thesis, data collection was performed at one occasion, and for each study data analysis was performed at two separate occasions. Firstly data describing the experience of fatigue (II) was extracted and analysed, second data describing the experience of daily life (I) was analysed.

Research ethics

According to Oliver (2003), people participating in research projects are the centre of the research process and it is their view that matters. In this licentiate thesis the women’s descriptions are the starting point of acquiring knowledge.

The team coordinator at the rehabilitation clinic contacted the women to obtain their informed consent about participation in the study. The information was both written and verbal. The nature of the study and the focus of the interview were explained to the women. They were informed that the participation was voluntary and that they could withdraw at any time. The women gave their informed consent and accepted to be contacted for arranging the interviews. The women’s comprehension of the information that was given could be ensured due to the team coordinator’s knowledge and experience of communicating with these women and promoting their well-being, which according to Cox White and Zimbelman (1998) is significant in ensuring comprehension. Also, when meeting the women for interviews the study nature was explained and the ethical aspects, comprehension and voluntary ness were brought forward once again. The informed consent was in this situation obtained both as verbal and as written. Confidentiality and an anonymous presentation of the findings were guaranteed.

Frank (1991) stated that illness is something to describe, to articulate and to share with others. Stories of living with illness need to be told to gain knowledge and shared understanding which can be applied when meeting expectations of people living with illness (Frank, 1995). Morse (2000) emphasized that sharing experiences with someone listening can have good
consequences for people with illness, due to feeling relief. According to Kvale (1997), the interviewer is obliged to ensure an atmosphere in which the interviewed feel safe in sharing and describing their experiences. To achieve this, a balance between searching for knowledge and ethical aspects is required, most importantly confidentiality. Being interviewed or asked to describe situations in life that are valuable to a person and have affected a person can most certainly bring forth feelings of distress (Polit & Beck, 2004) and by that considering the distress that the women with MS might feel, was an important issue when planning the interviews of this study. During the interviews in this study, women with MS described situations and feelings that in fact were distressing to them. When such a situation occurred, the interview was paused and the women were given an opportunity to decide whether the interview should continue. There was a possibility for the women to contact both me and the MS-team with questions that might arise after the conduct of interviews. Approval of performing this study (I, II) was given by the Regional Health Service Ethics Committee.

Methodological considerations

Pre-understanding is a concept which has to be visualized and taken into account. In the interpretive tradition, openness when approaching a text is inherent as a goal in the researcher’s pre-understanding. At the same time, the pre-understanding also undeniably directs the researcher (Wiklund et al., 2002). My pre-understanding related to the conduct of this study consists first and foremost of being a doctoral student in nursing with the experience of working as a registered nurse at a health care centre. My head supervisor is an experienced registered nurse, with an extended experience as a researcher in nursing science and my second supervisor is a physician and has extended experience of clinical rehabilitation concerning people with MS. Inherent as one aspect in our pre-understanding is a belief that people are interpretative and give meaning to their experiences. According to Lindseth and Norberg (2004), essence and meaning of a phenomenon would disappear without pre-understanding and the pre-understanding cannot be put a side in brackets. One aspect of my pre-understanding is also that my goal has been to participate in the narratives of the women with MS and by that put aside judgements of the factual and strive for open-mindedness. Ricoeur (1998) argued that being open-minded means risking one’s assumptions which are necessary in order to understand something new.

A purposive sample based on criteria was conducted to achieve narrations which would answer the aim of the study. Since the narrations were given by women, living with the secondary
progressive type of MS, living with documented MS-related fatigue and living an everyday life influenced by MS the sampling of narrations could be considered as relevant and in accordance with the aim of this study. According to Sandelowski (1995), purposive sampling does not mean choosing people, instead, it is the access to narrations of experiences that is considered. Conducting a purposive sampling means a search for richness, depth and variation of the phenomena under study. The sample in this study is homogenous and a more heterogeneous sample may have resulted in a different finding.

Narrative interviews were conducted in accordance with the aim of the licentiate thesis. Lindseth and Norberg (2004) emphasized that witnesses of essential meanings of a phenomenon cannot be heard without storytelling, which expresses the meaning that a certain phenomenon has in everyday life. The interviewees have to be aware of their lived experiences, willingly talk about them, and also be able to find the right words to express their lived experiences. In this study when it comes to the lived experience of fatigue, the women found it difficult to express and also to find the right words in order to describe fatigue in a manner that they believed others would understand. Due to this, in order to avoid misunderstandings, explorative and clarifying questions were of great importance during the interviews. Despite that the women found it hard to describe their experiences they clearly expressed the urgency of telling and the importance for them to take the opportunity to narrate their lived experiences. The interviews had richness, dept and gave variations of the phenomena and therefore a sample size of ten women with MS was considered enough to answer the aim of the licentiate thesis.

Phenomenological hermeneutic interpretation inspired by Ricoeur (1976) was used to analyze data, and according to Lindseth and Norberg (2004), this interpretation strives to reach an understanding of what it means to people to live their everyday lives. There are no expectations of finding one singular truth, instead, the goal is to find possible meanings. According to Ricoeur (1976), there is always more than one way to interpret a text. In this licentiate thesis, possible interpretations have been considered and compared (cf. Lindseth & Norberg, 2004) in critical discussion with peers (Ricoeur, 1976). Our goal has never been to reach an interpretative consensus, as interpretations are never final. Instead our goal has been to constantly revise our pre-understandings in critical discussion grounded in literature. According to Geanellos (1998, 2000), striving for group consensus is a positivist approach to control bias and this approach has no belonging in the interpretative tradition. According to Frank (2006),
dialogical research should never set out to finalize the other and the authorial word should never determine the fate of the people participating. The proposal of this study sets down one way to understand the meaning of women’s experiences of living with MS, it is not an omniscient finding since people’s lives are constituted by constant change. This licentiate thesis is not aimed at generalizing results but the findings can be plausible to similar situations (cf. Polit & Beck, 2004; Lindseth & Norberg, 2004).

FINDINGS

**Paper I The meaning of women’s experiences of living with multiple sclerosis**

The study presented in Paper I describes the meaning of women’s experiences of living with MS. This study suggests that the meaning of women’s experiences of living with MS can be understood as living with an unrecognizable body and trying to maintain power (i.e., the two themes). The bodies of the women with MS had become obvious and served as a hindrance when trying to pursue everyday life. Bodily changes, evident to others, imposed feelings of being met in a different way. This can be seen as an expression of a violated dignity but in the same time in order to protect the dignity a struggle is evident. In order to keep safe from harm and to protect the dignity, women with MS strive to maintain strength and power in the everyday life.

The experiences of women with MS were interpreted as living with an unrecognizable body, which was related to being directed by the ill body, having the will but finding it troublesome to perform and a feeling of being perceived as different. The body was described as unpredictable with a great impact on everyday life. Fearful and unusual sensations made it hard to understand what was happening to one’s own body. Loss of bodily control was evident and the loss of trust in oneself was described, due to the uncertainty of not knowing if the body would manage. Planning daily life in order to save energy was most important, but at the same time, due to the no-longer working body, planning was expressed as difficult. The dependency on others in daily life was expressed as hard and there were feelings of guilt due to not being able to engage in the family. Natural contacts with others were described as reduced and being avoided by others felt hurtful. Due to the no-longer working body there were feelings of being met with a different dialogue and body language. Women with MS expressed a feeling that others viewed them as changed, which did not correspond with their own view, and a wish for not being treated differently was expressed.
Trying to maintain power was related to seeking answers to unpredictability, having strength to fight, and seeing possibilities in life. The threat of illness was not accepted and refusal of letting the illness take control was described. The need for knowledge about the future was considered as urgent. The women expressed a desire of being met with honesty but often they felt alone with unanswered questions. When missing answers the women searched for information on their own. The women wondered why this illness had affected them. Feelings of being strong made it possible to live with the illness. The family was a strong source of power and the women struggled for the sake of the children. Struggling for the family and not giving in to the illness were expressed as not wanting to abandon the family that was there for them. The women with MS found relief when meeting others with MS. Meeting others sharing the similar experience led to not feeling different in the same time as an awareness of individual needs was raised. Women with MS hoped that the illness would not become any worse and they hoped for a cure. In their search for relief, women turned to alternative therapy. The women expressed that there was nothing else to do than try to live with the illness. Setting their focus on feasible things and things of importance in life made it possible to live with their illness. Taking it slow and stepwise made it possible to carry out things in daily life. The women expressed that asking others for help was a way of choosing to take part in life. The meaning of women’s experiences of living with MS is, in this study comprehended as living with a violated dignity contemporaneously as striving to protect the dignity. Women with MS live life with bodily obstacles that threatens the dignity in several ways, but there is also an apparent struggle where there is power to go about in life and to feel dignified.

**Paper II The meaning of fatigue for women with multiple sclerosis**

The study presented in Paper II describes the meaning of fatigue for women with MS and it suggests that the meaning of fatigue can be understood as experiencing the body as a barrier and experiencing a different absence (i.e., the two themes). Living with the body as a barrier and feeling absent and divided can be understood as if the surrounding world is unreachable. Not being able to fully participate in the surrounding world imposed feelings of being an outsider which in this study is interpreted as a form of suffering. Fatigue for women with MS seemed to imply that the body instead of working as an implement in order to manage everyday life the body had become an enemy of survival. The experience of fatigue for women with MS was interpreted as experiencing the body as a barrier, were a feeling of having a heavy body, a feeling of having the will but not the ability and a feeling of saving strength and needing to rest were present. Fatigue was described as a
whole bodily experience, which involved being fatigued from the hair down to the toes. An urge to let the arms and hands hang down was described and lacking ability to hold the body up straight was described. Muscles that was supposed to support the body felt weakened and legs feeling like several tons or having tons of sandbags tied to the leg was described. There was a feeling of being ruled by the body and not being able to manage. Making decisions and carrying out duties in daily life as before was no longer possible. Common daily tasks brought on fatigue, but the feeling of being fatigued after doing nothing was just as usual. Despite this there was a strong desire to go about in life as before and to be active. Feelings of insecurity and anxiety were expressed and the women felt like unreliable persons due to not being able to keep promises made to others. The whole family had it difficult and the family was described as suffering. Describing the fatigue was considerate as difficult and for others the feeling of being fatigued was believed as impossible to understand. The experience of fatigue differed considerably from experiences of being tired when healthy. It was an invisible feeling on the inside that did not show on the outside. There was a need of assistance from others and not being able to manage seemed to cause feelings of being a burden. The reduced energy implied a need to slow down. Economizing with the strength was hard due to losing energy without any effort. The fatigue did not disappear after rest or sleep but despite this unrelenting feeling, relief was still sought through resting, in hope for moments when being less fatigued.

Experiencing a different absence was related to an unusual and invisible feeling and a feeling of being absent. Fatigue was described as a suddenly appearing and never disappearing phenomenon and unusual feelings in the eyes led to a terrible dizziness which seemed to increase the fatigue, which made it impossible to stand up straight. The brain did not feel clear and there was a feeling of being struck by a sledgehammer. Problems in coordinating the body increased the fatigue and the fatigue was described as nothing like the feeling of tiredness felt before when healthy. There were feelings of being present but at the same time also being absent. This was a feeling of being split in two parts, were one part was participating while the other was watching. Due to feeling anaesthetized things appeared as just passing by and there were only in brief moments feelings of being focused and it was hard to look forward in time.
COMPREHENSIVE UNDERSTANDING AND REFLECTIONS

This licentiate thesis suggests that the meaning of women’s experiences of living with MS is connected with the manifestation of freedom in everyday life. All aspects of everyday life for the women with MS are touched by the illness and the women live with a fatigued body which has become most visible, although unrecognizable to them (I, II). The women with MS live with a body which no longer supports their involvement in everyday life and also threatens their dignity. Living with a threatened dignity for the women with MS, involves the unrecognizable body and not feeling in charge over the own body, a body which no longer can be trusted (I). Merleau-Ponty (1996) describes that people experience the surrounding world and their daily life through their bodies. When the body is functioning in accordance with a persons expectations it is invisible and taken for granted. But when the body no longer works, in accordance with personal expectations, people’s attention instead turns from the world and towards the body. The everyday lives of the women with MS are also strongly influenced by the unrelenting feeling of fatigue, which made it hard to participate in everyday life and gave rise to an unknown feeling of being absent and divided in two. The women described feeling anaesthetized and things appeared as just passing them by (II). From this it seems as if the women’s experiences of freedom in everyday life are first and foremost restrained by the body. According to Edlund (2002, 2003) facing the unfamiliar and when the demands of life are hard to handle people’s experience of freedom can be understood as restrained. Due to bodily failure the person’s experience of feeling freedom in life can be restrained and when people’s experience of feeling free is limited there is also a risk of not feeling dignified.

The women with MS felt that their bodies were unpredictable and they expressed no longer trusting themselves (I). The women’s ill and fatigued bodies direct life and demand a change in how the women with MS are to pursue their everyday life. They described that they felt ruled by their bodies, it was hard to manage, and making decisions and pursue ordinary daily tasks was no longer possible as before (II). The fact of not being able to go about in life as before or as expected can be seen as holding back the women’s sense of feeling free. This is in agreement with Söderberg et al. (1999) who showed that freedom in life for women with fibromyalgia is influenced by the lived body and changes in everyday life, and also Nordman (2006) has shown that people’s experience of freedom can be cut by outer elements demanding the person to live an undesired life.
The women with MS described natural contacts with others as reduced and they expressed being avoided by others as hurtful. Due to bodily changes, which were visible on the outside, the women felt being met by others with a different dialogue and body language. They felt that others saw them as changed, and this did not correspond with their own view (I). In the same time, since the fatigue was an invisible feeling that did not show on the outside, the women felt that it was impossible for others to understand their fatigue (II). From this, the women with MS seems to be faced with a paradox which concerns living with bodily restraints which is visible on the outside in the same time as the experience of fatigue cannot be viewed by others. When others view did not correspond with the women’s own feelings their experience of freedom can be understood as restrained, due to feeling viewed as different and missing sharing an understanding with others. Marcel (1973) writes that when intersubjectivity as shared understanding and affinity with others is in shortage there can be no perception of any freedom. The women with MS felt a dependency on others, which was expressed as hard, in order to go about in everyday life (I), they also expressed feeling like a burden due to not being able to manage (II). The women’s feelings of being a burden and feeling dependent can be seen as restraining their freedom. According to Edlund (2002, 2003) feeling dependent on others involves an encroachment in one’s private life and is accompanied by vulnerability and threatens a person’s freedom.

Freedom has by Frankl (1987) been understood as constituted with an inner and outer shape, where the inner freedom is not dependent on the outer freedom, due to a person’s ability to influence the own approach to meet the demands of life. Despite living a daily life strongly restrained by illness the women with MS strive not to let the illness control them. The women with MS are struggling to maintain power, they plan their daily life and they search for answers to unpredictability (I). This can be seen as if, in the lives of women with MS, despite the restraints, there are also aspects which promote or give freedom. For the women living with MS this shape of freedom can be a way to approach life, a way to meet the demands of illness, with the choice of involvement and taking part in everyday life. According to Edlund (2002, 2003) the no-longer obeying body restraints, without pardon, the person’s outer freedom. The women with MS live with a body which strongly restrains them and yet they act towards going about in life with a desire to be active and engaged (I, II). Due to feeling alone with unanswered questions they searched for information on their own and they also expressed that feeling strong made it possible to live with the illness (I). Despite experiencing an unrelenting fatigue the women still search for relief through resting, in hope for feeling less fatigued (II).
The different shapes of freedom in everyday life for the women with MS are therefore not to be seen as each others antagonists or opposites, instead this relationship seems to mean a feat for freedom as a feat to approach the conditions that the illness brings into the women’s everyday life. Ricoeur (1975) describes freedom and constraint as unseparated poles within between degrees of what is free and less free, what is constrained and less constrained. By this description, freedom is not a phenomenon which is experienced or not, rather it is the degrees of experiencing freedom that vary.

In this study the women with MS choose to take part in life and they choose to focus on what is experienced as strengthening in their everyday lives. By taking it slow and stepwise it was possible for the women to pursue ordinary tasks and they also choose to focus on things considered to be of importance (I). As understood by Ricoeur (1975), freedom means expressing the characteristics of one’s desires and focusing on what is desired in life. The choice of taking part in life instead of withdraw among the women with MS, can be understood as a way to approach the fact of needing help from others in order to involve in everyday life (I). Ricoeur (1975) describes an act to be free if the person can account for it, to oneself and also to others. In order to experience an act as free there has to be a meaningful reason for it. Edlund (2002, 2003) showed that the need to reconcile with receiving help from others, is in it self a sacrifice in order to experience meaning.

The women with MS viewed meeting others with similar experiences of living with MS as relieving and as not feeling different (I). This can be understood as important in order to experience freedom, due to recognizing one self with others and also finding ways to approach life in their own unique way. According to Frankl (1993) the demands of life are a question to the person and the need for solving problems and meeting life is a responsibility which a person always handles uniquely. Further, Frankl describes that a person’s freedom lies within the possibility to approach the different situations in life in a certain attitude. By this it is possible to experience freedom despite restrains in life. Freedom does not imply being living free from different conditions in life. Freedom instead means that a person is free to express an attitude towards life, when meeting the conditions of life. Despite feeling directed by the ill body the women with MS also choose to take the posture of hope. They live in hope for relief, they hope that the illness will not get any worse and they hope for a cure (I, II). This can be understood as finding a kind of an inner freedom involving a feat to go about in everyday life.
Since the possibility to go about in life, in a desired way, are challenged and important values, such as being there for the family and feeling involved in everyday life, are at stake for the women with MS (I, II), their freedom can be understood as threatened but also nurtured by their inner freedom containing a feat for important personal values in life. According to Marcel (1963) it is the condition of a threatened freedom which also nurture and shapes people’s experience of freedom in life. Freedom means a firm living in hope and giving the own life rich meaning. For the women with MS the feeling of being needed by family and children provides rich meaning which serves as a strong power to go about and engage in everyday life (I). Freedom according to Marcel (1963) is living in communion and fraternity. People experience freedom when being there for another, a free person is tied to the other in a mutual belongingness. The inner freedom for women with MS can be seen as a strong power which nurtures from the motivation of protecting values in life and holding back the constraints of illness. The women’s strive for being there for the family can be understood as a powerful source in the feat for freedom in everyday life. According to Marcel (1973) the freest act is one that is carried out under the strongest pressure and with the responsibility of another in focus.

In summery, the meaning of living with MS for women can be interpreted as if the women with MS are living with a restrained outer freedom in the everyday life and in the same time they seem to feat for an inner freedom where the values of life can be protected and used to go about in everyday life despite the demands of the illness. Further research is needed to gain more knowledge about the expression of freedom in everyday life for women with MS.

CONCLUDING REMARKS
This licentiate thesis focuses on women’s experiences of living with MS. Knowledge concerning how women with MS understand their everyday life increases the opportunity to formulate care in accordance with individual needs and expectations. Attention to women’s experiences of changing relations between their bodies, their self and the world is needed to address individual experiences, especially when living with a chronic illness like MS (cf. Toombs, 1992). This licentiate thesis provides new knowledge when it shows that the meaning of women’s experiences of living with MS can be seen as living with a restrained freedom in the same time as a feat for freedom in everyday life exists. The women’s bodies restrains their freedom in everyday life, and the women’s experiences of feeling viewed as different, avoided and met with a different dialogue and body language by others, stands as an obvious contrast against viewing and meeting people as equal standing despite differences. The
very opposite of feeling viewed as different and missing affinity with others, can be seen when this study suggests that meeting others with similar experiences of living with MS, recognizing one self and sharing an understanding is important to experience freedom in everyday life. This study shows that freedom in everyday life for women with MS has an outer and inner shape. In order to support the women’s strive for not being controlled by MS, it seems as if more knowledge is needed concerning women’s experiences of inner freedom. Basing caring actions on an understanding from the women’s lived experiences can most likely provide communication considered meaningful from the women’s angle of approach.
SUMMARY IN SWEDISH-SVENSK SAMMANFATTNING

Utryck av frihet i det dagliga livet:
Innebörden av kvinnors upplevelser av att leva med multipel skleros

Syftet med denna licentiatuppsats var att beskriva innebörden av kvinnors upplevelser av att leva med multipel skleros (MS). Denna licentiatuppsats fokuserar närmare på kvinnors upplevelser av dagligt liv (I) och upplevelsen av fatigue (II). Tidigare forskning visar att människor med MS beskriver sjukdomens oförutsägbarhet och upplevelsen av fatigue som de mest framträdande problemen i vardagen. Multipel skleros är vanligast bland kvinnor och forskning visar att kvinnor beskriver svårigheter med att få individuella behov tillgodosedda.

Eftersom att forskning gällande kvinnors upplevelser av att leva med MS är starkt begränsad fokuserar denna licentiatuppsats på kvinnors upplevelser.

I denna studie intervjuades tio kvinnor med sekundär progressiv form av MS. Urvalet var ändamålsenligt och kriterier för deltagande var: vuxna kvinnor med sekundär progressiv form av MS, kvinnorna hade dokumenterad MS-relaterad fatigue och deras dagliga liv var påverkat av MS. Kvinnornas ålder varierade från 43-59 år (md: 49) och de hade känt symtom i 9-39 år (md: 23). Den tid som passerat sedan diagnos varierade från 5-29 år (md: 18, 5). Nio av kvinnorna var gifta och en av kvinnorna levde i ett samboförhållande. Åtta av kvinnorna hade sjukpension och två av kvinnorna arbetade deltid. Samtliga kvinnor hade behov av hjälpmedel.

De intervjuer som genomfördes var av berättande karaktär och kvinnorna uppmuntrades till att berätta fritt om sina upplevelser av dagligt liv, upplevelser av symtom, tankar om sjukdomen, relationer till andra och upplevelser av fatigue i vardagen. Intervjuerna pågick under 40-60 minuter och de skrevs sedan ut till ordagrann text. Intervjutexten analyserades sedan med en fenomenologisk hermeneutisk tolkning. Med hjälp av denna metod beskriver innebörden av ett fenomen genom texttolkning. Genom texttolkning av levd erfarenhet kan en fördjupad förståelse för det undersökte fenomenet nås.

Den första delstudien beskriver innebörden av kvinnors upplevelser av att leva med MS. Denna studie föreslår att innebörden av kvinnors upplevelser av att leva med MS kan förstås som att leva med en oigenkännlig kropp och att försöka bibehålla kraft. För kvinnorna med MS hade kroppen blivit påtagligt märkbar och den fungerade som ett hinder i vardagen. Kroppliga förändringar som var synbara för andra medförde känslor av att bli bemötta på ett annorlunda

Den andra delstudien beskriver innebörden av fatigue (extrem trötthet) för kvinnor med MS. Denna studie föreslår att innebörden av fatigue kan förstås som att leva med kroppen som en barriär och leva i en annorlunda frånvaro. Att leva med kroppen som en barriär och känn sig frånvarande och tudlad kan förstås som att den omgivande världen inte går att nå. Att inte till fullo kunna vara delaktig i den omgivande världen medförde en känsla av utanförskap, vilket i denna studie tolkas som en form av lidande. Fatigue verkade medföra att kroppen, istället för att fungera som ett verktyg för att klara av vardagen, hade blivit en fiende. För kvinnor med MS tolkades fatigue som att kroppen blivit till en barriär, där känslan av en tung kropp, känslan
av att vilja men inte kunna och känslan av att spara kraft och behöva vila var närvarande.


Fatigue beskrövs som plötsligt framträdande och ovanliga sensationer i ögonen ledde till yrsel, vilken i sin tur ökade känslan av fatigue och gjorde det omöjligt att stå upprätt. Hjärnan var inte klar och där fanns en känsla av att bli slagen i huvudet med en slägga. Kvinnorna kände sig bedövade och det var svårt att se framåt. Där fanns också en känsla av att vara närvarande samtidigt som en frånvaro kändes. Detta var en känsla av att vara tadelad, där en del deltog medan den andra delen iakttog.

Denna licentiatuppsats föreslår att innebörden av kvinnors upplevelse av att leva med MS kan förstås som att leva ett dagligt liv med en frihet som är begränsad av den egna kroppen samtidigt som en strävan efter frihet i det dagliga livet finns. Den begränsade friheten involverar kroppen, relationer till andra och att inte kunna vara delaktig i vardagen på ett önskat sätt. Trots att kroppen inte längre fungerar väljer kvinnorna att vara delaktiga istället för att dra sig undan i vardagen. Samtidigt som deras frihet begränsas strävar kvinnorna efter en inre frihet som används för att möta sjukdomens krav. Relationen mellan den inre friheten och den
begränsade friheten innebär en strävan efter att vara fri att möta de problem som MS medför i kvinnornas vardag.
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REFERENCES


Krupp, L. B. (2006). Fatigue is intrinsic to multiple sclerosis (MS) and is the most common reported symptom of the disease. *Multiple Sclerosis, 12*, 367-368.


PAPER I
The Meaning of Women’s Experiences of Living with Multiple Sclerosis

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Abstract

The aim of this study was to describe the meaning of women’s experiences of living with multiple sclerosis (MS). MS is a chronic autoimmune disease of the central nervous system. The majority of persons living with MS are women. For women, living with MS has been described as difficult because of the uncertainty of the illness. In this study, we interviewed 10 women with MS and the interviews were analyzed with a phenomenological hermeneutic interpretation. In this study, we suggest that the meaning of living with MS for women can be understood as trying to maintain power and living with an unrecognizable body. The bodies of women with MS serve as hindrances in everyday life. Bodily changes evident to others impose feelings of being met in a different way, which can be understood as an expression of a violated dignity. At the same time, the women with MS struggle to protect their dignity.

*Key words:* multiple sclerosis, women, lived experience, phenomenological hermeneutics, body, dignity, nursing
The Meaning of Women’s Experiences of Living with Multiple Sclerosis

In this study, we report the findings of a qualitative inquiry. We interviewed 10 women with multiple sclerosis (MS) about their experiences of daily life. The interviews of the women with MS were analyzed using a phenomenological hermeneutic interpretation.

MS is a chronic autoimmune disease of the central nervous system with a course that varies and a prognosis that is uncertain. The main symptoms are numbness, visual impairment, lack of coordination, paralysis, fatigue, sphincter dysfunction and sexual problems (Schapiro, 2001; Vukusic & Confavreux, 2001). The symptoms have a strong impact on people’s bodily functions, daily activities (e.g., Hunyi & Nanayakkara, 2001; Månsson & Lexell, 2004; Steinman, 2001), and subjective experiences of the illness (e.g., Flensner, Ek & Söderhamn, 2003; Koch & Kelly, 1999b; Koopman & Schweitzer, 1999; Olsson, Söderberg & Lexell, 2005; Yorkston, Klasner & Swanson, 2001).

MS is most frequent among women (Minden, Marder, Harrold & Dor, 1993; Pryse-Phillips & Costello, 2001). According to Reynolds and Prior (2003), women with MS live life in a constant bodily negotiation where negative and positive sources are competing. Kralik, Koch and Eastwood (2003) stated, that for women with MS, recognizing and understanding the changed body to learn to live with illness, is a very lengthy process. Furthermore, Koch, Kralik and Eastwood (2002) stated that managing daily life is often perceived as hard due to uncertainty and lack of control.

Koch and Kelly (1999a) report that women with MS are faced with several losses in daily life, and to cope with the illness women with MS are often forced to make changes in their lifestyle. These changes are described as a movement from
Living with multiple sclerosis

being healthy and free to a dependency on others in daily living. Kralik et al. (2003) reported that women with MS often feel betrayed by their own bodies that no longer serve their needs and expectations. Koch and Kelly (1999b) point out that women with MS experienced feelings of humiliation in needing assistance with the most fundamental needs. Studies have shown that women with MS see relations and contact with others as very important in order to maintain their self-esteem and well-being (Crigger, 1996; Clingerman, Stuifbergen & Becker, 2004). Furthermore, these two studies show that women with MS were expecting support in trying to maintain and develop relations with others, relations which, in turn, decrease the feeling of being limited in daily life. Koch and Kelly (1999b) stated that, when meeting health care personnel, women with MS often experienced being met with deficient knowledge of their individual situation and needs. Women with MS did not experience recognition of their vulnerability and lacked space for feelings of grief and powerlessness when meeting health care personnel (Abma, Oeseburg, Widdershoven, Goldsteen & Verkerk, 2005).

Courts, Buchanan and Werstlein (2004) demonstrated that people with MS describe living with the illness before the diagnosis as a time of suffering because of the feeling of not being reliable in the view of others. After the diagnosis, it is an everyday struggle to maintain a daily living with the illness. According to Holland and Madonna (2005), MS has an impact on self-esteem, family relations, and relations with others. Research (e.g., Barton, Magilvy & Quinn, 1994; Miller, 1997; & Toombs, 1995) has shown that people with MS experience the unpredictability and loss of control in daily life as the most disturbing problem when trying to live with the illness. Furthermore, these three studies show that people with MS hope for
being less limited in everyday life to live in agreement with their individual expectations.

In summary, it becomes clear that, to meet the individual needs of women with MS and to alleviate the hindrance imposed by the illness, it is crucial that experiences of women with MS serve as a foundation. To gain this knowledge, the aim of this study was to describe the meaning of women’s experiences of living with MS.

Method

Participants and Procedure

Ten women diagnosed with secondary progressive MS participated in the study. The criteria for participation were adult women, living with a secondary progressive type of MS, and the fact that daily life was influenced by MS. The women’s ages ranged from 43-59 years (md: 49 years) and they had experienced symptoms for about 9-39 years (md: 23 years). The time after diagnosis varied from 5 to 29 years (md: 18.5 years). Nine women were married and one woman was cohabiting with someone. Eight women were receiving disability pension and two of the women were working part-time. All of the women were in need of mobility aids. The women’s participation was arranged through a rehabilitation hospital in the south of Sweden. At the rehabilitation hospital, the coordinator of the MS team contacted the women and informed them about the study and also invited them to participate. A letter was sent to the women to give information and to obtain informed consent. After acceptance of further contact, the first author (MO) telephoned each woman to arrange for an interview.
Interviews

Personal audio-taped interviews were conducted using a narrative approach (cf. Mishler 1986; Sandelowski, 1991). Seven women wanted to be interviewed in their home and three women preferred being interviewed in a quiet and separate room at the rehabilitation hospital. The women were asked to talk about their daily lives with MS, their experiences of symptoms, thoughts about their illness and relationships with others. They were also asked to narrate their experience of fatigue in daily life (Olsson et al., 2005). When needed, questions were asked to clarify their experiences. The interviews lasted between 40 and 60 minutes and were transcribed verbatim. Data collection was performed during 2002.

Ethical Considerations

Approval of performing the study was given by the Regional Health Service Ethics committee. Confidentiality and an anonymous presentation of findings were guaranteed.

The Phenomenological Hermeneutic Interpretation

To analyze the transcribed interviews, we used the method of phenomenological hermeneutic interpretation described by Lindseth and Norberg (2004) and inspired by the philosophy of Ricoeur (1976). Using this method, attempts are made to explain and, from there, understand the meaning of a phenomenon by interpretation of narratives. To gain understanding, a constant movement between the text as a whole and also its parts is a necessity. This method implies an interpretation as a certain form of understanding when applied to life expressions as a text. Through this interpretation a deeper understanding of a phenomenon can be gained from a dialectic movement between understanding and explanation, with the aim of reaching a new comprehensive understanding.
Phenomenological hermeneutic interpretation consists of three interrelated phases. The interpretation starts with a naïve reading of the text to gain a sense of its whole. This provides ideas for the structural analysis, which is characterized by dividing the text into meaning units linked to each other by content. Based on similarities and differences the meaning units are then organized into subthemes and themes, with an aim to explain the text.

Developed by and supported from the naïve reading, the structural analysis, our pre-understanding and literature, the text was interpreted in its whole and resulted in a new comprehensive understanding (cf. Lindseth & Norberg, 2004). The interpretation was conducted in an as open-minded manner as possible with an awareness of our pre-understandings as nurses and as a physician and as researchers in this area.

Findings

Naïve Understanding

Living with MS seemed to mean that the illness had captured the body. Daily life was filled with new boundaries and common daily tasks, often seemingly, out of reach. The no-longer working body was filled with new sensations such as fatigue, weakness, stiffness, and unsteadiness. To receive help and assistance from others to perform seemed in some way to be an intrusion into what used to be private. Feelings of being left out by others and not being able to participate as an equal seemed to exist, which implied feelings of loneliness. There were feelings of injustice over the fact that the illness was present. Struck with illness in the middle of life seemed to have great influence also on the lives of others, most importantly, the family. There seemed to be feelings of not being someone who others can trust and depend upon, which can involve feelings of losing a part of the self as it was experienced before
the illness. Feelings of pulling through the illness and refusing to let it dictate life seemed to be present.

**Structural Analysis**

The structural analysis resulted in two themes and six subthemes (Table 1). Themes and subthemes are presented in text with quotations from the interviews.

An Unrecognizable Body

The theme was constructed from the following subthemes:

*Being directed by the ill body.* When the illness arose there were feelings of dread due to not knowing what was happening to the body. Women with MS described that they no longer were in charge over the body, a body that felt unpredictable and had great impact on defining daily living. Fearful sensations such as being forced to drag one leg behind oneself, pricking sensations in the whole body and not being able to feel the skin, were described. Unusual flickering and pounding sensations in the eyes were described as a source of dizziness, making it almost impossible to stand up straight and move around. The women described an overwhelming feeling of being fatigued, where the whole body felt fatigued, and not being able to think clearly. The feeling was described as being strikingly different from any feelings of being tired felt before the illness. They were in need of immediate rest, but they also had to plan their daily activities to save energy. Because of not knowing if it would be possible to carry out plans that they deem important in their lives, the women shared feelings of no longer trusting themselves. Planning for daily life was hard because their bodies no longer work and the women admitted being afraid to think about how the future might turn out. In fear of the declining body, the women narrated that they saw exercise as a necessity that they
just had to do. They aimed to follow instructions of the health care personnel in to exercise but often the muscles felt weak and sometimes the women doubted the use of exercise.

I’m tired in my legs and it’s hard to move the legs… cannot stand on my legs and I have no power in my hands and I cannot write my own signature…so the illness goes its own way and it’s just to follow…to follow

You get insecure in yourself many times… I try… can I manage this… will I have enough strength to walk that distance… insecure… insecure… I have become in many ways

Having the will but finding it troublesome to perform. Changes in the labor situation were narrated and the women with MS expressed the sentiment that a part of the world was not meant for them. They described being dependent on others when performing daily tasks that they wished to have done themselves. Feelings of needing help from the family were expressed at the same time as it felt hard to ask the family for help. Not being able to engage in family activities led to feelings of guilt and failure and the women also felt that the whole family was suffering. Women with MS described that the family felt guilty doing things that the women were not able to take part in and women tried to make it easier for the family by being helpful. The will to engage in daily life was said to be crucial when using assistive devices, which the women also described as connected with inconvenience and, initially, also with embarrassment.
It [getting help during showering] feels like it crawls in below the human circle…where I don’t want anyone

It’s hard for the children when I feel like this…yes it’s…mum does not feel alright mum cannot walk…mum cannot manage…it feels like a failure in a way

*A feeling of being perceived as different.* Women with MS said that when they were no longer working, they felt isolated and lonely. Natural contacts with others were reduced and feelings of being avoided by others and, seeing former friends disappear were depicted as hurtful. They felt that others saw them as changed though inside they are the same person. Feelings of being ignored and not talked to by others were also described. There were feelings of being met with a different dialogue and body language, which the women saw as a result of the apparently no-longer working body. Being treated differently led to feelings of anger and frustration. Women said that it was hard for the family to understand, and there were feelings of not wanting the family to sustain more problems. It seemed as if the women had a great need of contact with someone who could understand and share their burden. They wished not to be viewed and treated differently by others.

They [people] don’t know how to address you…don’t have the courage to ask…I can imagine when a close relative passes away…there is almost nobody who has the courage to ask…we are cowards

It’s I who am ill not them [the family]…the day you expect the family to be ill…that is just to share your own grief…you could say…you will not get any better from this…you should never stop them from doing what they like
Trying to Maintain Power

The theme was constructed from the following subthemes:

Seeking answers to unpredictability. The women with MS described that they did not accept the threat of the illness and they refused to let the illness control them and their lives. Feelings of needing knowledge about how the illness was going to turn out were considered as urgent and feelings of not having confidence in health care personnel, which was related to not getting confirmation of experiences, were expressed. Wanting to be met with honesty and sincerity was crucial, but women with MS often felt being left wondering alone with unanswered questions, in fear of the unknown future. Due to lack of answers, women searched for information on their own. They described feeling angry and sad and wondered why this illness had affected them, of all people.

I cannot accept something that is threatening me…the illness…I consider it to be my worst enemy

They [health care personnel] could not confirm…they didn’t know…they had all different kinds of ways in telling that we don’t know and we cannot tell and I don’t think that is a good way to treat patients…I don’t know if it just would have been better just to say…you have MS

Why me…but that is life…it is unfair…I think in fact it’s unfair but this is my destiny

Having the strength to fight. Feelings of being strong and stubborn were described by the women with MS. These feelings were recalled to exist even before
the illness and now served as a source of power, which made it possible to live with the illness. Feelings of fighting as long as possible to continue working, despite the declining body and overwhelming fatigue, were described. The family was a strong source of power and especially the children’s dependency and expectations were a strong force to struggle in daily life (e.g., a reason to get up in the morning). Feelings of struggling for the family were expressed and the women could not give in and abandon their loved ones who in turn were there for them. Sharing problems in daily life with other people with MS led to a feeling of relief, being understood and not feeling different. Meeting and talking to others who shared their experience made life easier to deal with, but these also evoked an awareness of individual needs. The women with MS also expressed that life was easier when they felt understood by health care personnel.

The children have been my reason to struggle…if I had not had them I would just have stayed in bed…I would not have to get up…I would not have to see to it that they got to school…so in a way they have been my rescue

You cannot describe it [meeting others with MS] … it’s like heaven in some way to meet others with the same [experience of illness] you can recognize yourself all the time and things… you stumble and…daily life

*Seeing possibilities in life.* Hope that the illness would not become any worse was expressed and hope for palliation and cure made the women with MS, for lack of relief from medical treatment, turn to alternative therapy. They described feeling the need to accept and the women felt that there was nothing else to do but to try to live with the illness. When focusing on things that were feasible in life, the women said
that it was possible to live with the illness. They tried to see and do different things that they considered important. Planning and structuring their daily lives made it easier to do important things such as spending time with the family and committing themselves to their lives. Tasks in daily life were expressed as possible when taking it slow and step by step. Asking others for help and also letting others help were described as a feeling of choosing to take part in life. The need and necessity to use assistive devices were described and the women said that this made it possible to save strength to be able to manage daily life.

I believe that the key to accepting your illness is what is really important…with a lot of grief…I have lost a part of my health…others might lose a close relative or a husband or a wife

But you have to think…instead of thinking that your life is over…what do I like to do…how can I do it now…what do I have to change…in order to manage it…it’s just that everything you are going to do takes planning

**Comprehensive Understanding and Reflections**

In this study, we suggest that the meaning of the experiences of women with MS is to be understood as living with an unrecognizable body and trying to maintain power (i.e., the two themes). The bodies of the women with MS had become obvious and served as a hindrance when trying to pursue daily life. Bodily changes, those that were evident to others, imposed feelings of being met in a different way. This can be seen as an expression of a violated dignity, but at the same time, to protect the dignity a struggle is evident. To keep safe from harm and to protect the dignity, women with MS actively strive to maintain strength and power in daily life.
According to Edlund (1995) respect for people’s dignity becomes crucial when meeting people who are dependent on others in daily life. Edlund (2002) describes two dimensions of human dignity, where one dimension is seen as a constant and the other, a variable. The ground of human dignity lies within the constant dimension and is given to humans solely by being human beings. This fact gives humans a value that is absolute and under no circumstances questionable. In the dimension of variability, on the other hand, dignity is changeable and it can be eroded but also reestablished. Furthermore, Edlund (2002) claims that people have individual values in life that they recognize and hold as important, and when some of these values are damaged, a person can experience the dignity being violated. Söderberg, Lundman and Norberg (1999) show that the meaning of living with fibromyalgia for women means living with a threatened dignity, which is accompanied by a constant struggle for being dignified, a result that has similarities with the meaning of women’s experiences of living with MS.

Living with MS for women in this study means living with an unrecognizable body, which involves a feeling of being directed by the ill body in ways that are of strong importance when trying to go about in life. When the illness developed the women with MS felt fear because they did not know what was happening to their bodies. Frank (1995) has stated that experiencing the breakdown of the body is not only experienced as happening to one’s body, but most importantly, as happening to one’s life. Toombs (1992) describes that a person living with MS is living with a body that is unfamiliar and hard to interpret. Living with MS also means living with a body that no longer is integrated and in an intuitive manner interprets the world, which hinders a person’s ability to engage and pursue daily life. Women with MS experienced that they no longer could trust themselves; they do not even know if it
would be possible to go through with plans that felt important to them. According to Toombs (1992), the ill body means lack of control in important ways. The no-longer working body leads to evidence of dependency of the body and also vulnerability. Being limited and incapable of planning daily life in accordance to one’s wishes is a threat to the very self and significant to the state of living with an illness.

Women with MS felt fear because they did not know how the future would turn out. Toombs (1992) describes the uncertainty of living with progressive MS as an ever present threat. When a person’s actual present and future are characterized by uncertainty, a person’s experience of feeling whole is threatened. According to Toombs (2004), facing the fact of living with an illness that has no cure brings forth the most fundamental loss of control and feelings of helplessness. The illness not only serves as a threat to the body but also to the person’s self as being or feeling whole. The loss of bodily control causes a threat to the dignity, referred to as self worth and lack of bodily control in daily life can be understood as a threat against people’s integrity (Andersson, 1996). Women with MS live life with an obvious threatened bodily integrity, which can impose feelings of vulnerability.

A change in the labor situation was narrated by the women and they stated that a part of the world was not meant for them. Toombs (1995) describes that, along with the declining body, there are feelings of diminution and the sense of who we are is related to roles and goals that are of personal importance. A chronic progressive illness threatens to disrupt both professional and personal roles, which tends to reduce personal worth. Women experienced feelings of guilt and failure with not being able to engage in family activities. According to Toombs (1995), not being able to go through with plans and goals diminishes a person and brings forth feelings of guilt. Even though realizing that the ill body is out of one’s control, there are still
feelings of failure in not doing what ought to be done. Lack of ability to manage, ordinary daily life and being dependent on others can make a person experience a threatened dignity (Edlund, 1995).

Women with MS revealed that their declining body forced them to be dependent on others in performing their daily acts, which they would rather have carried out themselves. According to Marcel (1963) the feeling of solitude is essential when dignity is to be experienced. This fact is as essential as silence is to music. People need to have a safe space where they can find themselves in a most private and sacred way, where no one else should enter. To respect the dignity of women with MS, it is crucial to have an awareness of this grounded in a deepened understanding of the meaning of women’s experiences of having the will but finding it hard to do.

Being met and treated differently by others were seen by the women as a result of the no-longer working body. According to Toombs (1992), illness not only changes the person’s comprehension of his or her own body, but it also affects how others perceive the person who is ill. Women with MS experienced that others saw them as changed but inside they felt the same person. This feeling of being perceived as different is in this study understood as living with a threatened dignity and can bring forward feelings of not having the same value as others. Not being met with equality threatens the dignity of people (Eriksson, 1996). In the view of Marcel (1963), integrity is threatened when someone feels like an outsider and does not have a sense of belonging, which can be related to the feelings of women with MS.

The women with MS were trying to maintain power by seeking answers to unpredictability. Leder (1990) describes that when the body, because of illness, becomes the focus of attention, there is always a struggle for a desired ordinary state
where the body and the self are unproblematically unified. Protecting dignity by seeking answers can be seen as a way to endure an illness with an unpredictable nature. Women with MS experienced being left wondering alone in fear of the unknown future. Frankl (1993) explains that a person who is prevented from seeing and making predictions and forming goals about the future live life in a temporary existence. To find meaning in life people need to have a perspective about the future. Öhman, Söderberg and Lundman (2003) stated that living with chronic illness involves a search for explanation, which can be seen as a way to struggle for normality.

According to Buber (1994), human life is always realized in relation to others. For women with MS, expectations of the family and children’s dependency worked as a strong force to struggle in daily life. Feeling needed and confirmed by the family can be comprehended as strengthening the dignity of women with MS; the women had to struggle for the family who in turn was there for them. Eriksson (1996) stresses that people can experience absolute dignity by being there for another person. In order to experience dignity in life, responsibility for the other, built on a mutual relation, is recognized as crucial (Buber, 1994). Sharing experiences with others who lived with similar experiences of MS brought forward a feeling of being confirmed and not being met differently, which can be understood as being dignified. According to Marcel (1963), human dignity lies within the acknowledgment of the other, not confronted but most importantly greeted by the other by means of fraternity. Söderberg et al. (1999) showed that women with fibromyalgia experienced meeting others in a similar situation as a way of not being alone and also finding relief. Women with MS experienced a feeling of being understood and not felt sorry for by health care personnel, a feeling that in a way made life easier. According to
Marcel (1963), when recognizing the other, feelings of affirmation can be enhanced. In this view, dignity means acknowledging people’s dissimilarities instead of similarities. To preserve and protect the dignity of the other, there has to be recognition of the living tie that unites all people despite dissimilarities. By being confirmed and seen by others, Edlund (2002) emphasizes that the dignity of a person is protected.

Women with MS described hoping for palliation and cure to seek alleviation. Leder (1990) describes people’s need to seek alleviation as an act to meet the dysfunctional body. Instead of acting from the body, the person acts toward the body to unify power. In Marcel’s (1965) view, hope is not considered as a wish or a desire, instead it can be seen as a certain posture when trying to manage.

In conclusion, the meaning of women’s experiences of living with MS is, in this study, comprehended as living with a violated dignity contemporaneously as striving to protect that dignity. Women with MS live life with bodily obstacles that threaten the dignity in several ways, but there is also an apparent struggle where there is power to go about in life and to feel dignified.

Implications and Suggestions for Further Research

To formulate health care in accordance with individual needs of women with MS, the findings of this study should be considered. The need to formulate care founded on the experiences of women living with MS is urgent and a consideration of the findings of this study and the knowledge that it provides can serve as a valuable ground. Further research is needed to gain knowledge so that interventions that strengthen the experience of dignity among women with MS can be developed. It could be fruitful if future research would focus on the power that the women with MS express as strengthening and on how this power is to be facilitated.
References


Table 1

Overview of Themes and Subthemes Constructed from the Structural Analysis of the Interviews of Women with MS (n= 10)

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
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<tr>
<td>An unrecognizable body</td>
<td>Being directed by the ill body</td>
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<td>Having the will but finding it</td>
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<td>troublesome to perform</td>
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<td></td>
<td>A feeling of being perceived as different</td>
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<tr>
<td>Trying to maintain power</td>
<td>Seeking answers to unpredictability</td>
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<tr>
<td></td>
<td>Having the strength to fight</td>
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<tr>
<td></td>
<td>Seeing possibilities in life</td>
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The meaning of fatigue for women with multiple sclerosis

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The meaning of fatigue for women with multiple sclerosis

Aim. This paper reports the findings of a study that aimed to elucidate the meaning of fatigue for women with multiple sclerosis (MS).

Background. Living with chronic illness can involve giving up usual activities. MS is a chronic autoimmune disease of the central nervous system. Fatigue is a common experience among people with MS; however, little is known about the meaning of fatigue experienced by women with this condition.

Method. Ten women with MS were interviewed about their experience of fatigue. A phenomenological hermeneutic method influenced by Ricoeur was used to interpret the transcribed interviews.

Findings. The findings were presented in two major themes with five subthemes; experiencing the body as a barrier and experiencing a different absence. Fatigue seemed to give rise to an experience of being absent and divided into two parts. This also led to a feeling of not being able to participate in the surrounding world. The feeling of being an outsider and lacking the ability as a healthy person is interpreted as a form of suffering. Although the fatigue had a great impact on the women’s daily life, the women still hoped for some relief. Fatigue seemed to imply that instead of working as an implement to manage in the world the body has become an enemy of survival.

Conclusion. This study highlights the importance for nurses of understanding how women with MS experience fatigue, which is a prerequisite for communication based on a shared understanding. This awareness would enhance nurses’ opportunities to alleviate suffering. More research is needed to investigate what kinds of interventions can help these women to manage their everyday lives and to maintain a sense of normality despite their fatigue and illness. Such interventions should be subject to empirical evaluation research.

Keywords: multiple sclerosis, lived experience, women, fatigue, phenomenological hermeneutic interpretation, Ricoeur, nursing

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Introduction

This paper reports the findings of a qualitative inquiry with 10 women living with multiple sclerosis (MS) and who experienced fatigue. Illness is a subjective experience and may be a stressful event in people's lives (Conrad 1987). Living with chronic illness might involve giving up well-known activities, which are replaced by new routines that serve as constant reminders of the illness (Michael 1996). According to Corbin and Strauss (1987), chronic illness implies a separation between the person of the present and the person from the past. It affects the image of the self and can bring about a new situation that feels unfamiliar (Morse 2000a). Women with a long-term illness can have difficulties reconciling their former identity with the new identity of being ill (Kralik et al. 2001).

Multiple sclerosis is a chronic autoimmune disease of the central nervous system (Berhoux et al. 2001), whose symptoms include numbness, visual impairment, lack of co-ordination, paralysis, fatigue, sphincter dysfunction and sexual problems (Hunyi & Nanayakkara 2001, Steinhart 2001). MS usually begins between 20 and 40 years of age and affects women more often than men. Its course is unpredictable and its aetiology is unknown, but studies indicate that genetic, immunological and environmental factors are important (Soldan & Jacobson 2001). The physical symptoms of MS are important to a person's experience of the illness (Gulick 1997). There is no known cure, and so treatment is focused on immune modulation with beta-interferon, symptom management and various non-pharmacological interventions (Aikens et al. 1997, Miller 1997, Miller & Zezewski 2001).

We have found no previous research that has addressed the meaning of fatigue as experienced by women with MS. Narratives from these women might improve our understanding of the lived experience of fatigue and thereby allow health care workers to meet the expectations and needs of women with MS better.

Literature review

Fatigue is a common and disturbing experience for many people with MS (Krupp et al. 1995, Stuifbergen & Rogers 1997, Bakshi et al. 2000, Schwid et al. 2002) and has been reported as one of the worst symptoms of the illness (Fisk et al. 1994). Studies have shown that 78–87% of people with MS experience fatigue (Krupp et al. 1988, Schapiro 2001). Fatigue has been documented in many chronic illnesses such as cancer (Krishnasamy 2000), chronic obstructive airway disease (Ream & Richardson 1997), human immunodeficiency virus-infection (Rose et al. 1998), hepatitis C (Glacken et al. 2003) and fibromyalgia (FM) (Söderberg et al. 2002). Fatigue is a complex, disruptive and stressful subjective personal experience and has no general definition (Ream & Richardson 1997). According to Piper (1993), it can be considered an abnormal experience that has negative effects on bodily function and daily life. The origins of fatigue are both physical and psychological. Söderberg et al. (2002) emphasized that the meaning of fatigue as narrated by women with FM can be interpreted as a changed experience of the lived body.

The aetiology of fatigue in MS is not known (Krupp & Polina 1996, Bakshi et al. 2000) but is thought to be multifactorial (Schwid et al. 2002). According to Krupp et al. (1988), it may be exacerbated by heat and differs from the transient fatigue that healthy people experience. People with MS face a continual struggle against their fatigue (Nordeson 1998). Toombs (1995) described fatigue in MS as follows: ‘exhaustion means sitting in a chair and being literally unable to move’ (p. 9). Fatigue has been noted as a major reason for people with MS not being able to pursue full-time employment (Black et al. 1994, Jongbloed 1998, Kinkel 2000). Such people have described their experiences of fatigue as a paralyzing force, unrelenting and virtually ever-present (Stuifbergen & Rogers 1997). Fatigue has also been reported to affect cognition (Krupp & Elkins 2000) and decrease quality of life among people with MS (Fisk et al. 1994, Janardhan & Bakshi 2002, Miller 2003). Undoubtedly it significantly influences people’s daily lives (Stuifbergen & Rogers 1997, Bakshi et al. 2000, Bakshi 2003).

Fatigue in MS is subjectively experienced and may be misunderstood and misinterpreted by both family members and nurses (Stuifbergen & Rogers 1997). Krupp et al. (1988) stated that the subjective experience of fatigue is not related to the objective physical symptoms or neurological impairments. MS-related fatigue has been described as a time-consuming and all absorbing phenomenon that involves the whole human being (Flenser et al. 2003). Ward and Winters (2003) described it as an overwhelming sense of physical exhaustion that consumes people’s lives.

The study

Aim

The aim of this study was to elucidate the meaning of fatigue as narrated by women with MS.

Methodology

A phenomenological hermeneutic interpretation influenced by the philosophy of Ricoeur (1976) was used. In this approach, the researcher attempts to explain and understand
Participants

A purposive sample of 10 women diagnosed with secondary progressive MS (SPMS) participated in the study. They ranged in age from 43 to 59 years (md: 49 years). Nine women were married, and one was cohabiting. Two women were working part-time and eight were receiving a disability pension. All required mobility aids. Recruitment was arranged through a hospital rehabilitation clinic in the south of Sweden.

Data collection

Data collection took place in 2002. The team co-ordinator at the rehabilitation clinic contacted the women, gave them information about the study and invited them to participate. A letter was sent then to them to give information and obtain informed consent. The first author telephoned each person to arrange an interview. Three women were interviewed in a separate room at the rehabilitation hospital and seven were interviewed at home.

Personal tape-recorded interviews using a narrative methodology were conducted (Mishler 1986, Sandelowski 1991). The women were asked to talk about their daily lives with MS, their experience of symptoms, thoughts about their illness and relationships with others. They were also asked to narrate their experience of fatigue in daily life. When necessary, questions were asked to clarify their experiences. The interviews lasted between 40–60 minutes and were transcribed verbatim.

Ethical considerations

The regional health service ethics committee approved the study. The nature of the study was explained to the women and they were informed that they could withdraw at any time without this affecting their care. Confidentiality and anonymity were guaranteed.

Findings

Naive understanding

Living with fatigue in MS implied an impediment and limited the ability to live as before. It differed from the tiredness felt during health and was difficult to describe. Participants had to plan their daily live so that they would not lose too much energy and strength. Feelings of fatigue seemed always present and usually did not disappear with rest or sleep. Fatigue affected their relationships and the women reported that other people had difficulty understanding their condition. Women angered easily and expressed disappointment with themselves, which seemed to be related to a desire to do things that were out of their reach. They described how, because the feeling of being fatigued was ever present, there was little else to do but to accustom themselves to the situation.

Two major themes and five subthemes were identified (Table 1), and are presented below and illustrated by quotations from the interview texts.

Experiencing the body as a barrier

The theme ‘Experiencing the body as a barrier’ was constructed from three subthemes: a feeling of having a heavy body, a feeling of having the will but not the ability, and a feeling of saving strength and needing to rest.
A feeling of having a heavy body

Women with MS described fatigue as a whole bodily experience, which involved being fatigued from the hair down to the toes. They expressed an urge to let their arms and hands hang down. It was considered impossible to raise the arms up. Having shoulders that just wanted to sink down and a lack of ability to hold the body up straight were described. The muscles that were supposed to support the body felt weakened, and feelings of just wanting to lean the head because of weak muscles were described. Women described their legs as feeling like ‘several tons’ and feeling as if ‘several tons of sandbags’ had been tied to their legs:

I became more fatigued in the arms and then the power vanished, I could not in principle pick this cup up, lift the hands or the arms, the power, there was no power to raise them, so to speak, they were heavy.

Women described feelings of having a strained body with diminished power, which led to lack of perseverance. Their own bodies ruled them and they had to adjust themselves. There were feelings of being unable to manage and of feeling feeble.

A feeling of having the will but not the ability

Participants described how they were no longer able to make decisions and carry out duties in daily life as they could when healthy. They were fatigued when performing the most common daily tasks such peeling potatoes, doing laundry and ironing, hair washing, trying on clothes or just sitting down. They also described how they were fatigued after doing nothing, but there was a pervasive desire to go about life as before and to be an active person:

I could dance, but now I realise that it’s out of the question, can’t even imagine it. It feels devilish. For a while I thought that it would come back so I could, but now I can see that it’s best not to hope for it, because you get so disappointed.

Interviewees could no longer be reliable and could not always keep promises made to others. There were feelings of insecurity and anxiety, not knowing if it would be possible to do planned activities, and they expressed a feeling of leaving everything half done because of unpredictable fatigue. Women described frustration, stress, sadness and anger in themselves for not being able to do things as before:

But it’s not like that usual tiredness because this fatigue that comes, it comes so enormous. Then it’s like someone has pulled down the curtain, so to speak.

There was no fun in life, they felt bored and it was hard to find something interesting to do. They could not participate in family activities and believed this to be difficult for the rest of the family, and were aware that the whole family was suffering. They felt that it was impossible for others to really understand the fatigue because it was difficult to describe, and they often described their experiences by using metaphors. Women felt a need for assistance from others and they told how others had been helpful; however, this seemed to involve feelings of being a burden to others, when they were not able to manage by themselves:

I experience that I have become a totally dreary person. I feel that I can’t manage to pick up a hobby, I don’t feel like it. Before I could do a lot of things – I could sew, I could busy myself around the house – but now I don’t feel like it.

A feeling of saving strength and needing to rest

Women with MS expressed a need to slow down and to plan their daily lives in accordance with their reduced energy. They lost energy but this was not because of effort, and it was difficult to economize with their strength:

Plan, plan, plan, is what you have to do. Unfortunately, I plan where it will be easiest to drive and pick up groceries. There is a grocery [store] which I am not so fond of shopping in. There is a small, negligible uphill slope from the parking lot before entering the store, a ridiculous little slope, but it is like Mount Everest for me.

Fatigue seemed to mean a constant feeling that did not disappear following rest or sleep. Even after a whole night’s sleep, they this unrelenting feeling of fatigue remained:

I can lie down on the bed and think that I have been resting, but I haven’t. Instead, I’m still just as tired as before. I can’t make it go away by sleeping – it’s still there.

Despite the unrelenting feeling of fatigue, they sought relief by resting in order to experience moments of being less fatigued:

You try everything there is to get some relief... I don’t think it will cure me – that I have never believed – but maybe it could reduce the fatigue, maybe get some more power.
Experiencing a different absence

The theme ‘Experiencing a different absence’ was constructed from two subthemes: an unusual and invisible feeling and a feeling of being absent.

An unusual and invisible feeling

Women with MS described how the fatigue never disappeared. It appeared as a sudden feeling, like receiving a letter in the mail or:

The fatigue can appear through my feelings of being a rag that has been wrung out. I just sit down, closing my eyes and feeling, Oh, I can sit in a chair like that with the eyes closed for a long, long time.

They described an unusual feeling in their eyes, which involved a flickering and swimming sensation or an enormous pounding in the eyes that led to a terrible dizziness. They felt that their bodies were spinning, which caused nausea. The dizziness seemed to increase the fatigue and made it impossible to stand up straight:

And then the dizziness, like after having a bottle of wine to drink, no, but it feels awful, this fatigue and this unsteadiness.

Women felt that their brain was not totally clear and there was a feeling of being struck in the head by a sledgehammer. One woman described it in this way:

When you get fatigued in the legs, they will not obey at all, not me anyway, I (try to) lift a leg over an edge, or something like that. I think I'm lifting and lifting but nothing happens.

The feeling of being fatigued increased because of the extra effort of arranging their footsteps when walking. Women described how the fatigue was invisible and differed considerably from experiences of being tired when healthy. This was considered another strange feeling, differing from ordinary tiredness:

It doesn't always show on the outside that you're fatigued. Instead it's more here inside, so others can say, ‘What now, are you going to sit down?’ But I can't manage.

A feeling of being absent

Women with MS described how they felt as if they had been split in two parts. One part of them was participating while the other part was just watching:

If you imagine my fingers, if you imagine that the part of the left side stands guard, while the right side is the part, which is with me.

There were feelings of being present but at the same time being absent. Women could see everything but still felt that they were not there. There was a feeling of being anaesthetized and that things were just passing by:

But often it runs just beside you. It’s like you can see everything a little, so to speak, but you aren’t really there. You are there without being. That’s probably the normal. I can’t describe it.

Women described not being able to understand things that were happening around them. They could not fully participate during conversations because of lack of concentration, and felt fatigued in situations when many people were talking at the same time:

Sometimes when there’s a lot of people having a conversation, sometimes I experience myself as almost absent for a few moments. I think, ‘What did they just say?’, and it has got to do with the feeling of being fatigued – you are not really following, so to speak.

Only for brief moments could they feel totally focused. There were feelings of not being able to look forward in time, but of just thinking in the present moment:

It's just short moments that you are there 100%. Some days you are, sort of, half fatigued the whole day. Other days you're, sort of, totally clear for three or four hours.

Comprehensive understanding

The last phase of the interpretation involved the text being viewed in its entirety. Although the themes that elucidate the women’s lived experiences of fatigue are intertwined, they can also be considered as separate entities reflecting the meaning of the phenomenon of fatigue (van Manen 1997). The naive understanding, structural analysis and our pre-understanding were combined in a comprehensive understanding. This suggests that the meaning of fatigue, as narrated by women with MS, can be comprehended as living with a body as a barrier and with a feeling of ‘being absent’ in an unusual way, and experiencing the surrounding world as unreachable. Fatigue for women with MS is unlike what most of healthy people experience when tired, but the meaning that they give to this fatigue is similar to that of women with FM (Söderberg et al. 2002).

Reflections on the findings

The surrounding world is experienced through the body (Merleau-Ponty 1996). A full experience of the surrounding world requires a functioning body; when a body is not functioning, the surrounding world becomes unreachable to the person. The person’s image of the body changes from that felt when healthy to a different focus of attention during
illness (Leder 1990). A feeling of having a heavy body is experienced because of loss of energy and power. To manage in daily life the body is an implement, and a body part that will not obey a person’s will becomes objectified and viewed as no longer their own (Toombs 1995). The body for women with MS in this study is interpreted as a barrier in daily life, as no longer their own (Toombs 1995). The body for women will not obey a person’s will becomes objectified and viewed in daily life the body is an implement, and a body part that experienced because of loss of energy and power. To manage illness (Leder 1990). A feeling of having a heavy body is one of being captured and trapped in a body that no longer served one’s needs. The body was viewed not only as an ‘it’ (Merleau-Ponty 1996), but also as an enemy of survival (Frank 1995). Leder (1990) suggested that the experience of illness might accentuate the body and make it visible and apparent to the person. This stands in opposition to bodily experiences felt by healthy people, when the body is invisible and often taken for granted now needed extra effort.

Women with MS described experiences of insecurity and uncertainty because of the unpredictable fatigue. Toombs (1992) suggested that, when this happens, feelings of distrust arise. These might be related to suffering (Charmaz 1999) and have great impact on the person’s identity and self. Feelings of uncertainty can also mean losing an image of the future as taken for granted. Frankl (1969) described suffering as a personal and subjective experience, which is strongly connected to feelings of uncertainty. This can also be related to no longer trusting one’s own body. Women in this study described fatigue when performing the most common tasks in daily life. This mirrors findings about fatigue in FM, as Soderberg et al. (2002) stated that women with FM experienced fatigue as an interfering obstacle in everyday life and something that influenced the ability to live in a normal way. Toombs (1992) explained how objects that earlier were considered useful might become obstacles and decrease the person’s ability, because actions that were previously taken for granted now needed extra effort.

Women with MS had experiences of not being able to participate in family activities. Leder (1990) noted that changes in the usual experience of the world, because of inability to perform, disrupt the connection to other people. This disruption is linked to the fact that people often share pleasures with others. It seems as if the fatigue hinders sharing or communion with others. Women also expressed feelings of guilt when not being able to perform activities.

Charmaz (1999) stressed that feelings of guilt appear when an illness also disrupts the lives of others.

Loss of abilities can be connected to suffering. Younger (1995) emphasized that suffering is closely linked to loneliness and experience of being an outsider. A person who suffers might lose a sense of belonging, and this might also bring feelings of a life torn apart. Fromm (1976) explained that people who lose the ability to control their own acts are no longer in charge of their world; instead they are forced to view the world from outside. Loss of control over the body means loss of autonomy and is related to suffering (Charmaz 1999). When loss and illness dominate life, people experience suffering. Suffering can also be related to loss of wholeness and personal autonomy (Frank 1995). Women with MS expressed a desire to live as before, but because to they were unable to do so they felt that there was no way out. They felt trapped and also threatened, which is a form of suffering, according to Kahn and Steeves (1986). According to Morse (2000b), people’s experiences of suffering are closely related to time and loss.

A feeling of saving strength, and a need to rest, seemed to mean that, despite the unrelenting feeling of being fatigued, women still hoped for moments of feeling less fatigued. According to Marcel (1965), hope is closely connected to despair and the two seem to coexist. Hoping for possible relief can mean an ability to see beyond the present situation. Women described a feeling of losing energy due to no effort, but even after resting the fatigue was still present. This supports the findings of Flenner et al. (2003), who described MS-related fatigue as always living with less energy and strength in daily life. Despite this unrelenting fatigue, women with MS in our study still tried to find relief. Hope of possible relief was also prominent in the meaning of fatigue for women with FM (Soderberg et al. 2002). Hope for relief might be seen as a motivator to try anything that might ease the fatigue (Leder 1990). According to Marcel (1965), hope implies no guarantee against disappointment, but it can lead to openness to possibilities in an uncertain situation. Women had feelings of having their lives directed by the fatigue, which might be interpreted as entrapment or being imprisoned. As well as being imprisoned by the fatigue, they seemed to be fighting back. Barnard (1995) discussed the dialectic between chronic illness and disability as constant defiance, even when knowing that the outcome might not be as wished.

Women described how, even if there were no hope for cure, they felt an urge to try anything to gain some relief. Hope can be considered an inner power, separate from optimism, that works as an energising force in a person’s life (Urquhart 1999). According to Frankl (1969), hope is essential to see
the meaning of life and it enables people to overcome difficult situations. Morse and Pentrod (1999) described hope as related to concepts of enduring, uncertainty and suffering. According to Öhman et al. (2003), hope and hopelessness coexist: hope offers a way to endure, whilst hopelessness increases a person's suffering.

Women described unusual sensations in the body, which seemed to impact on the self and the way in which the world was perceived. When the body no longer functioned in a familiar way, a person's attention was drawn towards their own body. Merleau-Ponty (1996) stated that the surrounding world is not experienced by an intellectual mind alone, but it is through bodily perceptions that we read and interpret the environment. When the body no longer functions and interprets the world as before, the perception of the world may be altered. Women told how the fatigue was invisible to others and this made it harder for others to understand. Similarly, Soderberg et al. (1999) showed how invisible symptoms of FM led to feelings of not being believed by others. When illness was not apparent, others treated the sufferer as though the condition did not exist. The lived body is both a subject to the person and an object to others' external gaze (Leder 1990). This in turn impacts on other people's understanding because it is difficult to understand something that is invisible.

Women with MS described a feeling of being split in two, one part participating in life and the other just watching. In the moment of being present, they also felt an absence. This can be interpreted as if the altered focus of attention prevented them from experiencing full presence, because of the embedded fatigue. Younger (1995) stressed that the feeling of being separate or detached is a form of suffering. The women felt that things were passing them by. Only during brief moments could they maintain total focus, which led to not being able to participate fully in conversations because of lack of concentration. Such feelings of being absent were related to the notion that the no longer functioning body was viewed by the person as an unrecognizable image of the former self (Merleau-Ponty 1996).

Methodological considerations

The findings of this study lack generalizability but may be considered for their applicability in similar situations (Polit & Hungler 1999). As our intention was not to generalize results, a sample size of 10 women was considered sufficient for a deep analysis. As there is always more than one way to interpret a text, a plausible interpretation is insufficient: the interpretation needs to be more likely than other interpretations (Ricoeur 1976). The interpretation in this study was considered plausible based on our experiences with and understanding of people living with chronic illness and MS.

Conclusion

This study shows that fatigue for women with MS has a great influence in everyday life and is an experience that differs from any feeling experienced when healthy. Therefore, healthy people may find it difficult to understand what they experience. This includes health care personnel, who could take into consideration the findings of this study and thereby minimize the risk of relating women's experiences of fatigue to their own experiences of tiredness. This would help them to meet the needs of women with MS. Everyone has bodily limitations and our views of health and illness are subjective. Health care personnel tend to talk a language of symptoms, but women with MS talk about having difficulties performing acts that healthy people take for granted. It is therefore important for nurses to understand the fatigue experienced with MS, so that they can empathize with these women's reality, and increase communication based on shared understanding. We suggest that this awareness is a good starting-point for nurses in supporting women with MS. More research needs to be done to investigate what kinds of interventions help women with MS to manage their everyday lives and to maintain a sense of normality despite their fatigue and illness. There is also a need for empirical research to evaluate these different kinds of interventions.

Issues and innovations in nursing practice

What is already known about this topic

- Living with a chronic illness often involves experiences of being fatigued.
- Fatigue is a common experience among people with multiple sclerosis.
- There is little research about the meaning of fatigue in chronic illness.

What this paper adds

- Fatigue implies a feeling of not being able to participate in the surrounding world.
- To have a will to do things but to lack the ability is interpreted as suffering.
- Women with multiple sclerosis experience fatigue as different from tiredness.

The meaning of fatigue

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Acknowledgements

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References


Issues and innovations in nursing practice

The meaning of fatigue


In Olsson et al. (2005) an author’s job title was incorrect on page 7. The correct details are:

Siv Söderberg PhD RNT
Assistant Professor, Department of Health Science, Luleå University of Technology, Boden, Sweden

In Wong (2005) the author qualifications were incorrect on page 210. The correct details are:

Kwan Wai Wong BSN MSc RN
Frances K.Y. Wong BSN MA(Ed) PhD RN
Moon Fai Chan BSc PhD

We apologize for these errors.

References