Meanings of Women's Experiences of Living with Multiple Sclerosis

Malin Olsson
Meanings of Women's Experiences of Living with Multiple Sclerosis

Malin Olsson
Division of Nursing
Department of Health Science
Luleå University of Technology
Sweden

Luleå 2010
For my family
<table>
<thead>
<tr>
<th>CONTENTS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ABSTRACT</strong></td>
<td>1</td>
</tr>
<tr>
<td><strong>ORIGINAL PAPERS</strong></td>
<td>3</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td>5</td>
</tr>
<tr>
<td>Theoretical perspective</td>
<td>5</td>
</tr>
<tr>
<td>Experiences of living with chronic illness</td>
<td>7</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>8</td>
</tr>
<tr>
<td>Experiences of living with multiple sclerosis</td>
<td>10</td>
</tr>
<tr>
<td>Women’s experiences of living with multiple sclerosis</td>
<td>11</td>
</tr>
<tr>
<td>Experiences of fatigue among people with multiple sclerosis</td>
<td>13</td>
</tr>
<tr>
<td>Experiences of wellbeing among people with multiple sclerosis</td>
<td>14</td>
</tr>
<tr>
<td>Experiences of treatment among people with multiple sclerosis</td>
<td>16</td>
</tr>
<tr>
<td><strong>RATIONALE</strong></td>
<td>17</td>
</tr>
<tr>
<td><strong>THE AIM OF THE THESIS</strong></td>
<td>18</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td>18</td>
</tr>
<tr>
<td>Setting</td>
<td>18</td>
</tr>
<tr>
<td>Participants and procedure</td>
<td>18</td>
</tr>
<tr>
<td>Paper I and II</td>
<td>18</td>
</tr>
<tr>
<td>Paper III and IV</td>
<td>19</td>
</tr>
<tr>
<td>Interviews</td>
<td>19</td>
</tr>
<tr>
<td>Paper I and II</td>
<td>19</td>
</tr>
<tr>
<td>Paper III and IV</td>
<td>20</td>
</tr>
<tr>
<td>The phenomenological hermeneutic interpretation</td>
<td>20</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>22</td>
</tr>
<tr>
<td><strong>FINDINGS</strong></td>
<td>23</td>
</tr>
<tr>
<td>Paper I</td>
<td>23</td>
</tr>
<tr>
<td>The meaning of women’s experiences of living with multiple sclerosis</td>
<td></td>
</tr>
<tr>
<td>Paper II</td>
<td>25</td>
</tr>
<tr>
<td>The meaning of fatigue for women with multiple sclerosis</td>
<td></td>
</tr>
<tr>
<td>Paper III</td>
<td>27</td>
</tr>
<tr>
<td>Meanings of feeling well for women with multiple sclerosis</td>
<td></td>
</tr>
<tr>
<td>Paper IV</td>
<td>28</td>
</tr>
<tr>
<td>Meanings of treatment for women with multiple sclerosis</td>
<td></td>
</tr>
<tr>
<td><strong>COMPREHENSIVE UNDERSTANDING AND REFLECTIONS</strong></td>
<td>29</td>
</tr>
</tbody>
</table>
METHODOLOGICAL CONSIDERATIONS 37
CONCLUDING REMARKS 39
SUMMARY IN SWEDISH - SVENSK SAMMANFATTNING 41
ACKNOWLEDGEMENTS 49
REFERENCES 51
PAPERS I-IV

DISSERTATIONS FROM THE DEPARTMENT OF HEALTH SCIENCE,
LULEÅ UNIVERSITY OF TECHNOLOGY, SWEDEN
Meanings of Women’s Experiences of Living with Multiple Sclerosis

Malin Olsson, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden

ABSTRACT
The aim of this doctoral thesis was to describe meanings of women’s experiences of living with multiple sclerosis (MS). It focuses specifically on the women’s experiences of daily life (I), the experience of fatigue (II), experiences of feeling well (III) and experiences of treatment (IV). Narrative interviews were conducted with 25 women living with MS and the interviews were analyzed from a phenomenological hermeneutic interpretation.

For women with MS, living with an unrecognizable body meant that the deterioration of their bodies had become clear and served as a hindrance in daily life. The experience of fatigue seemed to mean that the body instead of working as an implement in order to manage daily life had become an enemy. These experiences included bodily changes, which were evident to others, and imposed feelings of being met in a different way. The ill body threatens the women’s dignity and they expressed being avoided by others as hurtful. Despite the fact of all aspects of daily life are being affected by illness, the women with MS nevertheless do find ways to experience feeling well. Feeling well, for women with MS can be understood as finding a pace where daily life goes on and the illness is not the dominant experience.

This thesis suggests that meanings of women’s experiences of living with MS can be comprehended as a movement between the two dimensions of having a value and feeling unimportant to others. In the dimension of having a value, feeling well is brought forward, meanwhile the dimension of feeling unimportant to others, implies suffering in the daily lives of women with MS. For these women recognizing oneself as valuable and sharing an understanding are important in order to feel dignified in daily life and to experience feeling well.

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


Papers I–III has been reprinted with the permission of the publisher concerned.
INTRODUCTION
This doctoral thesis focuses on the lived experience of women with multiple sclerosis (MS). Research concerning meanings of women’s experiences of living with MS is limited, therefore the aim of this thesis is to describe meanings of women’s experiences of living with MS. Multiple sclerosis is most common among women and research show that women find it hard to convince others about their individual needs. People living with MS have described the unpredictability of the illness and the experience of fatigue to be the most difficult problems to face in daily life (cf. Miller, 1997; Toombs, 1995).

Theoretical perspective
This thesis has the focus of people’s experiences of living with illness as described by Söderberg (2009). According to Söderberg, it is crucial to distinguish illness as a concept from the experience of being ill and living with illness. The individually subjective experience of being ill is often hard to mediate to others, and there is reason to assume that it never fully can be shared with other people. However, by starting from people’s descriptions of the experience of being ill, it is possible to gain a deeper understanding, which in turn can be decisive for the implementation of care and nursing. According to Connolly (2001) an important area of clinical practice, the discipline of nursing, is indebted to the ground-breaking research in nursing which has been focusing on peoples lived experiences. Research concerning lived experience impacts on practitioner preparation, and the ongoing professional development in nursing should not be underestimated when it comes to meeting up with the needs of ill people in daily life. Toombs (1992) brought forward the importance of acknowledging the lived experience of the body in relation to being ill, and according to Connolly (2001) the ill body which resists healing and treatment is rejected by a culture valorising productivity and this non-ideal body serves as the ultimate threat to predictability, productivity and control. Toombs (1992) pointed out the
profound difficulty in constructing a shared world of meaning between the ill person and healthcare personnel. According to Connolly (2001) the lived body of the person seeking help from the healthcare system, has not been viewed as the most reliable source of information in itself. Since being misunderstood undermines people’s confidence in their lived experience, and threatens their relationship to their reality, the focus on peoples lived experiences is crucial if the goal is to approach people’s daily lives in a serious manner.

This thesis is conducted within the field of nursing science and has a lifeworld phenomenological approach. The lifeworld is a central concept in phenomenology and phenomenological research sets goals for achieving a deeper understanding of the meaning of everyday experiences. The lifeworld, in this view, is central to human understanding and according to Husserl (2004) the lifeworld 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 consciousness and the world, develops with Merleau-Ponty’s phenomenology of the body. In the view, of Merleau-Ponty (1996) the Cartesian split of the mind and body is rejected. In contrast, the body according to Merleau-Ponty, constitutes 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 possess a body as an object thing among other objects. Instead a person is her/his body and the surrounding world is experienced as lived through the body.

According to Merleau-Ponty (1996) the aim of phenomenology 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,
according to Ricoeur, phenomenology 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 Uggla (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, for example experiences of living with a chronic illness.

Experiences of living with chronic illness

Research focused on living with chronic illness shows a considerable impact on people’s daily lives (Thorne & Paterson, 2000). The experience of illness has been described as if the ordinary daily life becomes interrupted and as a fundamental loss of wholeness is salient in people’s lives (Toombs, 1992). 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 (Bury, 1982; Charmaz, 1987, 2002, 2006; Michael, 1996). Chronic illness has been shown to restrict people in their everyday lives, and it is known that this restriction causes experiences of loneliness and feelings of being excluded from living in a community with others (Jumisko, Lexell & Söderberg, 2007; Sexton & Munro, 1988; Öhman, Söderberg & Lundman, 2003). 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 can eventually 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. Jumisko, Lexell and Söderberg’s (2009) research pointed at the possibility of feeling well despite being ill when the unfamiliar daily life becomes familiar. Several studies (Charmaz, 2006; Corbin & Strauss, 1987; Johansson, Ekebergh & Dahlberg, 2008; Kralik, Koch, Price & Howard, 2004; Thorne & Paterson, 2000) pointed out that people want to live life as before and they find new ways of learning to live with the illness, when the changes that are brought forward by illness can be included in daily living. A chronic illness that has been shown to affect people’s daily life is multiple sclerosis.

**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 (Compston & Coles, 2002; 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; Australia and New Zealand Multiple Sclerosis Genetic consortium, 2009). 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 ethnical factors are of significance. Northern Europe, North America, Australia, and New Zealand have the highest prevalence of MS, 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, glatiramer acetate, natalizumab and symptom management (Comi, 2009; Flensner & Lindencrona, 2002; Hemmer, Nessler, Zhou, Keiseier & Hartung, 2006; Miller, 1997; Miller & Jezewski, 2001; Olsson, Piehl, Swanberg & Lidman, 2005; Oreja-Guevara et al., 2009; 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 (Borkoles, Nicholls, Bell, Butterfly & Polman, 2008; Isaksson & Ahlström, 2008; Toombs, 1992; Yorkston, Klasner & Swanson, 2001). Lerdal, Gulowsen Celius and Moum (2008) showed that people who live with MS perceive reduced physical function as the most important factor related to the progression of the illness, and 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 the 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 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 describe problems in their interaction with health care personnel, this since the symptoms of the illness vary strongly. People with MS also describe experiencing symptoms being wrongly diagnosed, and emotional needs 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) demonstrated 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 requires power and energy, which people with MS often lack (Flensner, Ek & Söderhamn, 2003; Leino-Kilpi, Luoto & Katajisto, 1998). 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 troublesome problem. Despite this, living with MS, involves a hope for becoming free from limitations. According to Isaksson and Ahlström (2008) people with MS despite losses and emotional distress, experience hope for the future and Irvine, Davidson, Hoy and Lowe-Strong (2009) and Malcomson, Lowe-Strong and Dunwoody (2008) showed that people with MS over time change their values and outlooks on life as they learn to cope with the illness.

**Women’s experiences of living with multiple sclerosis**

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 in retaining 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 relations with others. Support from others and stability in a 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; Kirkpatrick Pinson, Ottens & Fisher, 2009). Still, loneliness has been pointed out as a common experience among women with MS and declining bodily function and lack of social support are related to women’s experiences of feeling lonely (Beal & Stuifbergen, 2007).

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 and hope to persevere (Dyck, 1995; Kirkpatrick Pinson et al., 2009; Reynolds & Prior, 2003). Focusing on personal goals, maintaining roles of value, trying different life styles to keep alive earlier interests, and maintaining relationships have been viewed as a positive way to experience wellbeing. Despite this, feelings of frustration, anger, and grief are often present as the body does not
work as it should, and also because these women are not able to participate effectively 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, Oeseburg, 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. In contrast, Kirkpatrick Pinsons et al. (2009) research showed that women with MS feel that they have the fortune of being listened too and being asked the right questions.

Experiences of fatigue among people with 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 (Bakshi et al., 2000; Krupp & Polina, 1996; Krupp, 2003) but there are no doubts that fatigue has a strong impact on people’s lives (Bakshi et al., 2000; Blaney & Lowe-Strong, 2009; 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 &
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 deterioration. 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). Lee, Newell, Ziegler and Topping (2008) showed that there is little evidence-based advice that can be offered people who live with MS in order to manage fatigue.

Experiences of wellbeing among people with multiple sclerosis

Studies (Brunet et al., 1996; Forbes, While, Mathes & Griffiths, 2006; Miller & Dishon, 2006) call attention to the problems of measuring well-being and advocate research that focuses distinctly on expressing people’s personal experiences. The research of Fawcett and Lucas (2006) presented the importance of healthcare based in individual needs and Toombs (2004) states that knowledge concerning personal experience is de facto a prerequisite for supporting well-being among people with MS. For people who live with MS the adaptation to uncertain and unpredictable changes in their functional status is shown to be
difficult and also related to quality of life (Stuifbergen, Blozis, Harrison & Becker, 2006). Research (Devins, Edworthy, Seland, Klein, Paul & Mandin, 1993; Sprangers, de Regt & Andries, 2000) has shown that people living with MS have a lower quality of life than those living with other chronic illnesses because the effect on daily life is greater in MS. Similar to this, Nicholl, Lincoln, Francis and Stephan (2001) revealed that people with MS experienced lower quality of life than people living with other chronic illnesses, and the lower life quality was related to the loss of energy that people with MS experience and also problems concerning social relations. For people with MS, the severity and progression of illness as well as high functional limitations were associated with low quality of life and for people who had lived with MS for a long time the functional limitations increased (Aronson, 1997; Beiske et al., 2007; Gottberg et al., 2006; Pfennings et al., 1999; Stuifbergen et al., 2006).

For people with MS occupational conditions, changes in economic circumstances, depression, fatigue and disabilities are factors which have been shown to affect quality of life in a negative manner (Amato, Ponziani, Rossi, Liedl, Stefanile & Rossi, 2001; McCabe & De Judicibus, 2005; Miller & Dishon, 2006). In contrast medical treatment for depression, coping with stress and exercise has been pointed out as tending to improve the quality of life among people with MS (Hart, Fonareva, Merluzzi & Mohr, 2006; Stuifbergen et al., 2006; Sutherland, Andersen & Morris, 2005). Self-management has been shown to impact upon quality of life among people with MS, and being able to understand and to take part in treatment decisions has been shown as a positive experience for people with MS. In contrast, a lack of information has been shown as a barrier to self-management and control over daily life (Bishop, Frain & Tschopp, 2008). The research of Russell, White and Parker White (2006) shows that people who are able to find personal meaning to why they have been afflicted by MS experience a higher quality of life and wellbeing than people who
believe that meaning was impossible to find. Higher levels of education seemed to be associated with finding meaning and the ability to search for answers to existential questions. Employment and continuity of meaningful roles which were socially defined as productive, was also shown as powerful in personal meaning making.

Experiences of treatment among people with multiple sclerosis

The manner in which people with chronic illness experience themselves as received and treated by others are of crucial importance, and also decisive if the fundamental loss of wholeness which is a common feature among people who are ill is to be relieved, or on the other hand, increased (Råholm & Lindholm, 1999; Toombs, 1992). Similar to this, Thorne, Con, McGuinness, McPherson and Harris (2004) discussed the experience of illness as providing insight into communications that are perceived as helpful or unhelpful in order to live well with a chronic illness. For people who live with MS, fear was described as a prominent experience that seemed to escalate when people with MS doubted the legitimacy of their symptoms and questioned their own competence. Receiving validation of their experiences of symptoms is described as helpful and in contrast, feeling dismissed implies feelings of fear and loss of self-confidence. Studies (Courts et al., 2004; Koopman & Schweitzer, 1999; Miller, 1997; Toombs, 1992) have shown that the unpredictability of illness has important consequences for the person in daily life, and the experience of being met with deficient help has been reported. For people with MS the varying personal needs in daily life, are considered as affecting their experience of being treated according to ones needs in encounters with healthcare personnel in a negative way.

Fong, Finlayson and Peacock (2006) pointed out the importance of an appropriate response to the changing needs among people with MS. The specific
concerns among people with MS were related to the fear of increasing incapacity and the fear of being a burden on caregivers. Borkoles et al. (2008) showed that people with MS feel discomfort by being watched by other people who look at them because of their difficulties concerning physical ability. When exploring the stigma that people with MS experience in social relations, Grytten and Måseide (2006) showed that people with MS felt ignored or, in contrast, having people overemphasize the illness in encounters. Yorkston, Klasner and Swanson (2001) pointed out that people with MS experience a change in their communication with others. The communicative participation was shown to be limited and there was an experience of being treated differently and not being able to keep up with how healthy friends live their lives. It has been shown that people with MS in situations purposely conceal that they have MS, and this is considered as one way to influence the feeling of being socially judged and deprived of a social belonging in favour of guarding their sense of self (Grytten & Måseide, 2005).

**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 the experience of fatigue in MS is predominantly quantitative. The experience of fatigue is described as an invisible and misunderstood phenomenon without relation to objective physical symptoms, which increase the risk of the expectations of people with MS not being met. The literature review reveals a lack of knowledge concerning meanings of living with MS for women, with the focus on daily life, the experience of fatigue, experiences of feeling well and treatment. This thesis 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 the support that increases wellbeing and health among women with MS.

THE AIM OF THE DOCTORAL THESIS

The aim of this doctoral thesis was to describe meanings of women’s experiences of living with multiple sclerosis. It focuses specifically on the women’s experiences of daily life (I), the experience of fatigue (II), the experience of feeling well (III) and the experience of treatment (IV).

METHODS

Setting

This study was conducted in the southern part of Sweden (I, II) and in the northern part of Sweden (III, IV). In the study (I-IV) women with secondary progressive MS participated.

Participants and procedure

*Paper I and II*

Ten women diagnosed with secondary progressive MS participated in the studies presented in Paper I and II. The sample was purposive, and the criteria for 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 for 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 for an interview.

**Paper III and IV**

Fifteen women diagnosed with secondary progressive MS participated in the studies presented in Paper III and IV. The sample was purposive, and the criteria for participation were; adult women, living with a secondary progressive type of MS, and the fact that their daily life was influenced by MS. The women’s ages ranged from 35 to 70 years (md: 54 years) and they had experienced symptoms for about 12 to 37 years (md: 32 years). The time after diagnosis varied from 7 to 34 years (md: 24 years). Eight women were married, three women were cohabiting with someone and four of the women were single. Ten women were receiving disability pension, three women were receiving state pension and two of the women were working part-time. All of the women were in need of mobility aids or aid equipments. The women’s participation was arranged through a hospital in the northern part of Sweden. At the hospital, a registered nurse contacted the women and informed them about the study and invited them to participate. A letter was sent to the women to give information and to obtain informed consent. After acceptance of further contact, each woman was contacted by telephone to arrange for an interview.

**Interviews**

**Paper I and II**

The interviews in Paper I and II were conducted in 2002 and 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 separate room at the rehabilitation clinic. The interviews lasted between 40-60 minutes. The narratives were later transcribed verbatim.

**Paper III and IV**

The interviews in Paper III and IV were conducted in 2007 and personal audio-taped interviews were conducted using a narrative approach (cf. Mishler 1986; Sandelowski, 1991). All of the women preferred to be interviewed in their homes. The women were asked to talk about experiences of feeling well in their daily lives when living with MS. They were also asked to narrate their experiences of treatment. When needed, questions were asked to clarify their experiences. The interviews lasted between 40 and 60 minutes and were transcribed verbatim.

**The phenomenological hermeneutical interpretation**

In order to analyze the transcribed interviews (I-IV) the method of phenomenological hermeneutic interpretation described by Lindseth and Norberg (2004) and inspired by the philosophy of Ricoeur (1976) was used. In 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 of reaching 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 pluralistic 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. The meaning units are condensed and abstracted into formulated meaning units. Based on similarities and differences in meaning, the formulated meaning units are grouped together. The groups are then compared and 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 is interpreted in its whole with the result of a new comprehensive understanding (Lindseth & Norberg, 2004). In this doctoral thesis, data collection was performed on two occasions, and for each study data analysis was performed on four separate occasions. In the data collection performed in 2002, data describing the experience of fatigue (II) was first extracted and analysed, and second data describing the experience of daily life (I) was extracted and analysed. In the data collection performed in 2007, data describing the experience of wellbeing (III) was first extracted and analysed, and second data describing the experience of treatment (IV) was extracted and analysed.
Ethical considerations

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 doctoral thesis the women’s descriptions are the starting point for acquiring knowledge. The women who participated gave their informed consent both verbally and in writing. The nature of the study and the focus of the interview were explained to the women and the ethical aspects, comprehension and the voluntary aspects were brought forward. They were informed that the participation was voluntary and that they could withdraw at any time. 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, something which can be applied when meeting expectations of people living with illness (Frank, 1995). Morse (2000) emphasized that sharing experiences with someone who listens can have good consequences for people with illness, due to feelings of relief. According to Kvale and Brinkmann (2009), 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, 2008) and 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 halted and the women were given an opportunity to decide whether it 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 for performing this study (I, II) was given by the Research Ethics Committee of Lund University, and by the Regional Ethics Review Board (III, IV).

**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). To the women with MS, the deterioration of their bodies had become clear 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 at the same time in order to protect dignity a struggle is evident. In order to keep safe from harm and to protect their dignity, women with MS strive to maintain strength and power in 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 difficult and there were feelings of guilt due to not being able to engage with the...
family. Natural contacts with others were described as being reduced and being avoided by others felt hurtful. Due to the limitations imposed on their bodies 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 a refusal to let the illness take control was described. The need for knowledge about the future was considered as urgent. The women expressed a desire to be met with honesty but often they felt alone with their unanswered questions. When they were not given 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 who shared similar experiences led to not feeling different, while at the same time it raised an awareness of individual needs. 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 things slowly, step by step made it possible to perform tasks in daily life. The women expressed how asking others for help were 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
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, had become an enemy of survival.

The experience of fatigue for women with MS was interpreted as experiencing the body as a barrier, where 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 total 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 also noted. Muscles that were supposed to support the body felt weakened and legs feeling as though they had several tons of sandbags tied to them was mentioned. 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 difficulties and the family was described as suffering. Describing the fatigue was considered as difficult and for others the feeling of being fatigued was believed to be 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 one’s 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 rest, in the hope of experiencing moments of 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 latter was described as being nothing like the feeling of tiredness that was experienced 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, where one part was participating while the other was watching. Due to feeling anaesthetized, things appeared as though they were passing by and feelings of being focused occurred only momentarily, making it difficult to look forward in time.
Paper III Meanings of feeling well for women with multiple sclerosis

The study presented in paper III describes meanings of feeling well for women with multiple sclerosis and it suggests that meanings of feeling well for women with MS can be understood as finding a pace where daily life goes on. Feeling well meant that the women had the power to do the ordinary, they felt contented and they felt peace and harmony. For women with MS, feeling needed and feeling understood was central to feeling well despite living with limitations and hindrances caused by illness. Finding a pace where daily life goes on means that women with MS feel well when the illness is kept in check. By finding a balance in life where illness is not the dominant experience, the women with MS feel well. Feeling well for women with MS was strongly related to how the body felt, and feeling well meant being able to get up in the morning and starting a good day. They recounted how doing ordinary things, such as being able to sit on the balcony, getting properly dressed and having dinner with the family made them feel well. Women with MS felt well when their bodies functioned with some predictability, when they were able to manage and trust themselves in everyday life. They described getting used to the fact that a lot of things were no longer taken for granted and the women narrated approaching daily life as it is and learning how to live. The women with MS felt well when they were at home alone, feeling peaceful and released from external demands and they felt harmony through living at their own pace and listening to their bodies. Feeling needed by others meant that the women could realize their value and they felt well when they could help another fellow being. For women with MS feeling well was interpreted as feeling understood and they described how they felt well when they met others with similar experiences and by having a close relationship with their families.
Paper IV Meanings of treatment for women with multiple sclerosis

The study presented in paper IV describes meanings of treatment for women with MS. In this study it is suggested that meanings of treatment for women with MS can be understood as containing two concurrent dimensions where treatment from others can mean recognizing oneself through confirmation as well as being disconfirmed due to missing togetherness with others (i.e., the two themes *experiencing oneself as a valuable person and experiencing oneself as diminished*). It was salient that the women with MS experienced confirmation by being understood by others, and as a contrast, the women found themselves disconfirmed by being questioned and met with lack of understanding.

The experience of treatment for women with MS was interpreted as *experiencing oneself as a valuable person*, which was related to being seen for whom you are and getting help without giving explanations. Women with MS expressed feelings of recognition and being welcomed by others to take part as a person who is no different from others. It felt good to be treated by others in the same way as they had been treated when healthy. Instead of being stared at, the women with MS expressed how they felt welcomed by others. For women with MS being needed by others meant growing as a person and when meeting others who were in the same situation there was a certain understanding. Women with MS expressed meeting healthcare personnel who were striving to provide the best possible treatment. When being approached and recognized by healthcare personnel the women expressed feeling visible and welcomed as an individual. The women described that they did not have to present constant explanations about how they wanted help in daily life and they sensed that it was uncomplicated for the healthcare personnel to assist another fellow human being with their personal needs.
In addition to the dimension of confirmation, there is also the dimension of being disconfirmed where feelings of being questioned and met with lack of understanding is salient in the women’s daily life. The experience of treatment for women with MS was interpreted as experiencing oneself as diminished and they described being treated differently from when they were healthy and they believed that others did not understand them. They lacked understanding from others since the illness, with its exhaustion and pain was invisible, and in contrast they felt that others pitied them as an ill person due to the obvious difficulties with their bodily condition. Women with MS narrated an experience of not being welcomed and they felt that there was no room for them in the healthy society. The difference between being able to walk and sitting in a wheelchair was striking to the women who expressed being ignored and met in a ruthless way. The women with MS narrated that no one cared about their experiences and they constantly had to explain their needs in daily life. Advice from homecare personnel seemed unnecessary and the women expressed feeling like a burden to the homecare personnel who were stressed by their daily necessities. Due to the unpredictability of the illness, the women with MS described how it was hard trying to explain personal needs and felt that their daily needs were underestimated.

**COMPREHENSIVE UNDERSTANDING AND REFLECTIONS**

The overall aim of this doctoral thesis was to describe meanings of women’s experiences of living with MS. This thesis suggests that meanings of women’s experiences of living with MS can be comprehended as a movement between the two dimensions; having a value (I, III, IV) and feeling unimportant to others (I, II, IV). The women with MS strive to safeguard their threatened dignity concurrently as they experience themselves as excluded by others. In the dimension of having a value, feelings of feeling well are brought forward, meanwhile the dimension of feeling unimportant to others, implies suffering in
their daily lives. Despite the fact that these two dimensions differ in substance they should not be seen as opposites, rather a movement between the dimensions exists (I-IV).

For the women with MS, all aspects of daily life are touched by the illness. The women live with a fatigued body which has become most visible, although unrecognizable to them (I, II). They live with a body which no longer supports their involvement in daily life and also threatens their dignity. Edlund (2002) pointed out the meaning of human dignity as two dimensional. On one hand, human dignity is unconditional, and on the other it is relative. The former of these two dimensions of dignity is described as constant, while the latter is described as changeable with an inner and an outer shape. Living with a threatened dignity for the women with MS, involves the unrecognizable body which they feel they have no control over, that is, a body which no longer can be trusted in daily life (I). Merleau-Ponty (1996) describes how people experience the surrounding world through their bodies. When the body is functioning in accordance with a persons expectations, it is invisible and taken for granted. However, when the body no longer functions, in accordance with personal expectations, people’s attention instead turns from the world and towards the body. For women with MS, this can mean that the ill body is standing in the way of pursuing ordinary projects which used to feel familiar in daily life. The body in illness becomes present by performing in an unrecognizable manner and therefore threatens the dignity of the women. For the women with MS, the body which no longer acts in an expected way implies feelings of being hindered instead of being able to engage in the treasured projects of daily life (cf. Leder, 1990).

The daily lives of the women with MS are strongly influenced by the unrelenting experience of fatigue, which made it hard to participate in daily life and gives rise
to a strange feeling of being absent and divided in two. The women described feeling anaesthetized and things appeared as just passing them by (II). It could be understood as if the experiences of dignity in daily life among women with MS are restrained by the body, a finding which corresponds to the research of Söderberg et al. (1999) who showed that the dignity of women with fibromyalgia (FM) is threatened by bodily disruption and loss of bodily integrity. According to Toombs (1992) the relation between body and environment changes during illness. This change implies that the environment is perceived differently during illness than when being healthy, in the sense that the environment is sensed as unfamiliar to the person’s earlier preference. For people who live with an ill body, the possibilities of action shrink and the alternatives that were earlier available decrease. The women with MS felt that their bodies were unpredictable and they expressed a feeling of no longer trusting themselves (I). They described how they felt ruled by their bodies, that it was hard to manage, and making decisions and pursue ordinary daily tasks was no longer possible in the same way as before (I, II). It could be understood as if the fact of not being able to go about in life as before or as expected can be seen as holding back the sense of feeling free for the women with MS. Söderberg et al. (1999) showed that freedom in life for women with FM is influenced by the lived body and changes in daily life. The diminished freedom in daily life of the women with MS can be understood as related to their threatened dignity. For women with MS, the unfamiliar demands of the body are difficult to manage and the fact of not having the ability to carry on living as when they were healthy curtailed their experience of freedom (cf. Frankl, 1987).

The women with MS described their natural contacts with others as being reduced and they expressed being avoided by others as hurtful. Due to bodily changes, which were visible on the outside, the women experienced that they were 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 how they experienced themselves (I, IV). At 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 them and their experience of fatigue (II, IV). From this, the women with MS seemed to be faced with a paradox which concerns living with bodily restraints which are visible on the outside at the same time as the experience of fatigue cannot be viewed by others. The women felt misunderstood, questioned and pitied by others (IV). According to Merleau-Ponty (1996) the world is not only related to the person, instead the body is understood as double. As well as being lived, the body is an object to others. A person’s experience of oneself can therefore be seen as related to others perceptions of the person. From this, the body could be understood as the person’s representation of the self towards others. Toombs (1992) describes that the loss of an upright posture brings forward feelings of loss of integrity and autonomy. Bodily impairment can for the ill person mean feelings of inequality in relation to others. The disruption of the unified body-world system includes a disruption in being able to do the ordinary and connotes a feeling of being out of sync with people whose physical capacities are intact (Toombs, 2001).

The feelings of being ignored and avoided by others among the women with MS (I, IV) can be understood from Frank (1991) who describes how relations to others come under stress due to illness, and how the experience of the ill person can be constituted by subtle denials and silence from others. According to Edlund (2002) dignity in its changeable form, is influenced and related to the views of contemporary culture and society. The body is often considered as a symbol of dignity due to its ability to perform as expected by culture and society. Although for the person who is ill, the body that no longer performs as expected can imply a violated dignity and a sense of suffering. For women with MS, feeling viewed as different and being disconfirmed due to missing togetherness with others
implies an experience of feeling diminished (IV). This could be seen as if the women’s experiences of being disconfirmed and excluded by others imply a shortage of mutuality, which can be understood as a form of suffering. Suffering threatens the integrity of people. It is described as a highly individual experience and for the person it implies a struggle to understand what has happened to life (Cassel, 1999, 2001).

For women with MS, being disconfirmed involved a feeling of being met in a ruthless way by others and due to being ill, they felt a lack of strength to defend themselves from people who questioned them (IV). Cultural and social norms can imply suffering for the ill person, due to the assumption that these norms decide if people who are ill will be met with acceptance or isolation and pity (Cassel, 2004). According to Younger (1995) people’s experiences of suffering are nourished by feeling estranged from others. The feeling of being estranged means, for the estranged person, an unexpected negative treatment from others. However, the estrangement does not imply a durable state of not being connected to others. The experience of estrangement instead ranges from alienation to full connectedness with others. Although persons who feel estranged are undeniably left with feelings of abandonment, they long to be connected.

The need for experiencing oneself as highly thought of, and feeling reckoned as important by others is vital among people. In experiencing oneself as important in relation to others, an acknowledgment from other people has to exist (Weil, 1994). For women with MS the experience of feeling unimportant to others engenders their suffering when being faced with being ignored and receiving a lack of respect. The daily lives of women with MS seem not affected by bodily disruption alone, but also by the view of others and in the manner in which the women with MS experience themselves as received from others.
The women with MS felt a dependency on others, which was expressed as difficult, in order to go about in everyday life (I). They expressed feeling like a burden due to not being able to manage and experienced their needs in daily life as underestimated and they missed the right kind of help (IV). Feelings of dependency and missing the right kind of help can be understood as engendering a form of suffering for the women. These experiences of women with MS have similarities with the research of Eriksson (1993) who pointed out the concept of suffering from care, as containing feelings of being cared for in an undesirable way. In suffering from care, a lack of freedom related to dependency exists. For the ill person dependency implies feelings of unworthiness and feelings of lacking genuine relations. The meaning of suffering related to healthcare has been shown to imply feelings of not being regarded as a whole human being with individual needs and also not to being seen as someone who is within their own agency (Arman, Rensfeldt, Lindholm, Hamrin & Eriksson, 2004; Sundin, Axelsson, Jansson & Norberg, 2000). The women with MS described a longing for a relation where they could be listened to instead of receiving advice irrelevant to their daily needs (IV). This can be understood according to Marcel’s (1950) discussion on the experience of communication. For Marcel the unreal communication means that the person who I express myself to lacks the ability to reflect back and to confirm my experience. For the women with MS it seems as if there is a gap between their experience of being ill and the perspective of the personnel which are to meet the women’s needs in daily life. The experience of MS can be considered to consist of an experience which is hard to share and implies hindrances in the establishment of a shared understanding between the person who is ill and others. Feeling cared for in accordance with one’s needs ought to be considered as a human birthright and the lack of reciprocity should not be underestimated in engendering feelings of being misunderstood among women with MS (cf. Marcel, 1950; Toombs, 1992; Weil, 1994).
This thesis suggests that concurrent to being excluded by others, the women with MS strive to safeguard their threatened dignity. The experience of feeling valuable, in contrast to suffering from feeling unimportant to others, can be understood as eliciting feeling well among women with MS (I, III, IV). Despite living a daily life strongly restrained by illness the women with MS strive to not let the illness control them. They are struggling to maintain power, they plan their daily lives and they search for answers to unpredictability (I). When women with MS manage to find a pace where daily life goes on and the illness is not the dominant experience, they can feel well despite being limited. They described feeling well as being related to approaching life just as it is and learning how to live (III). This can be seen as if, in the lives of women with MS, despite the restraints, there are also aspects which promote wellbeing. For the women living with MS this 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 Frankl (1987) the ability to influence the approach to meet the demands of life are a prominent feature among people. In his attempt to understand the meaningless and the meaningful in people’s lives, Frankl described how people can find ways to preserve their inner freedom and dignity by the conviction that life is good despite its adversities (Frankl, 1987, 1993). Women with MS experience feeling well despite living with bodily limitations due to their illness. They experience themselves as strong persons, focusing on the possibilities of life and when they feel that they receive relevant support in daily life the experience of being dependent on others decreases (I, III, IV). This can be seen as if women with MS, despite being hindered in daily life, reckoned themselves as living a perceived good life where they strive to meet the different conditions in life imposed by the illness. It could be understood as if the women’s experiences of inner freedom lie within the possibility to express an attitude towards life, when meeting the conditions of their illness (cf. Frankl, 1993).
The women with MS viewed meeting others with similar experiences of living with MS as being a relief and as feeling valuable (I, III, IV). This can be understood as important in terms of experiencing feeling well, due to recognizing oneself among others. For women with MS this can be understood as though feeling well is strengthened when they find themselves met as individuals. According to Buber (2004) a genuine understanding of the other is possible only in an immediate relation where the other is accepted as unique and different from me. In relations where people can find themselves respected as different, it is also possible to find oneself. People’s feelings of being accepted do depend on the experience of being confirmed in a mutual understanding (Buber, 1997). For women with MS, feeling needed and understood by others was a strong source of feeling well (III). This can be understood as strengthening the women when striving to safeguard their dignity. For women with MS their experience of feeling well is brought forward by feeling dignified. The women’s experience of dignity is formulated in relation to others and the women seem to experience dignity by being confirmed as well as confirming others. The women’s experiences of feeling appreciated and respected by others can be understood as engendering vitality in their daily lives (cf. Edlund, 2002; Weil, 1994).

In summary, meanings of living with MS for women can be comprehended as if women with MS strive to safeguard their dignity concurrently as they are being excluded by others. These two dimensions bring forward experiences of feeling well respective suffering in daily life, which means a movement between having a value and feeling unimportant in relation to others. For the women with MS, all aspects of daily life are touched by the illness. They experience a fatigued body which has become most visible, although unrecognizable to them. The ill body threatens their dignity and they expressed being avoided by others as hurtful. The daily lives of women with MS seem not affected by bodily disruption alone, but also by the view of others and in the manner which the women with MS
experience being received by others. Despite this, women with MS manage to find a pace where daily life goes on, and when the illness is not the dominant experience they can feel well. This can be seen as if, in the lives of women with MS, despite the restraints, there are also aspects which promote feeling well. The women with MS viewed feeling needed and understood as feeling valuable. The feeling of having a value can be understood as important in order to experience feeling well.

**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. My main supervisor and co-supervisor are experienced registered nurses, with extended experience as researchers in nursing science. Inherent as one aspect in our pre-understanding is a belief that people are interpretative and give meanings 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 aside in brackets. According to Dahlberg and Dahlberg (2003) pre-understanding cannot be cut off, but the intentional threads which guide human understanding ought to be slackened. In order to allow an understanding of a phenomenon as it is, bridling is used to interpret the presentations belonging to the phenomenon. 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, or as described by Dahlberg and Dahlberg (2003) to not make definite what is indefinite.

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 doctoral thesis. Lindseth and Norberg (2004) emphasized that witnesses of essential meanings of a phenomenon cannot be heard without storytelling, which expresses meanings 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 the fact 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, depth and gave variations of the phenomena and
therefore a sample size of 25 women with MS was considered enough to answer the aim of the 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 doctoral 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 thesis sets down one way to understand meanings of women’s experiences of living with MS, it is not an omniscient finding since people’s lives are constituted by constant change. This doctoral thesis is not aimed at generalizing results but the findings can be plausible to similar situations (cf. Lindseth & Norberg, 2004; Polit & Beck, 2008).

CONCLUDING REMARKS
Multiple sclerosis is commonly described as a long-lasting illness with no definitive cure as well as leading to a lack of health among the people inflicted. Yet describing MS as a long-term illness, does not express meanings of experiencing individual needs in daily life. It fails to capture what bodily chaos
and uncertainty means for women who live with MS and it fails to capture the phenomenon of feeling well concurrently as being ill. This doctoral thesis focuses on meanings of 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 themselves and their environment is needed to address individual experiences, especially when living with a chronic illness like MS (cf. Toombs, 1992). This doctoral thesis provides new knowledge when it shows that meanings of women’s experiences of living with MS can be seen containing a strive to safeguard their dignity concurrently as they are being excluded by others. These two dimensions bring forward experiences of feeling well respective suffering in daily life, and for women with MS this means a movement between having a value and feeling unimportant in relation to others. The women’s feelings of being avoided and unimportant to others, stands as an obvious contrast against viewing and meeting people as equals despite differences. The very opposite of feeling viewed as different and missing affinity with others, can be seen when this thesis suggests that meeting others with similar experiences of living with MS, recognizing oneself as valuable and sharing an understanding is important to experience feeling well and to feel dignified in everyday life. Basing caring actions in daily life on an understanding from the women’s lived experiences can most likely provide support which is considered meaningful from the women’s angle of approach.
Kvinnors upplevelser av att leva med multipel skleros

Syftet med denna doktorsavhandling är att beskriva innebörder av kvinnors upplevelser av att leva med multipel skleros (MS). Avhandlingen fokuserar på kvinnors upplevelser av dagligt liv (I), fatigue (II), att må bra (III), och bemötande (IV). 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 sina individuella behov tillgodosedda. Eftersom att forskning gällande kvinnors upplevelser av att leva med MS är begränsad fokuserar denna doktorsavhandling på kvinnors upplevelser.

I delstudierna I och II intervjuades tio kvinnor med en 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 deltids. I delstudierna III och IV intervjuades femton kvinnor med sekundär progressiv form av MS. Urvalet var ändamålsenligt och kriterier för deltagande var; vuxna kvinnor med sekundär progressiv form av MS, samt att det dåliga livet var påverkat. Kvinnornas ålder varierade från 35-70 år (md: 54) och de hade känt symtom i 12-37 år (md: 32). Den tid som passerat sedan diagnos varierade från 7-34 år (md: 24). Åtta av kvinnorna var gifta, tre av kvinnorna levde i ett samboförhållande,
och fyra var ensamstående. Tio kvinnor hade sjukpension, tre statlig pension, och två av kvinnorna arbetade deltid.


I delstudi I beskrivs innebörden av kvinnors upplevelser av att leva med MS. I denna studie tolkas innebörden av kvinnors upplevelser av att leva med MS som att leva med en oigenkänlig kropp och att försöka bibehålla sin kraft. För kvinnorna med MS hade kroppen blivit nära närvarande och var ett hinder i vardagen. Kroppsliga förändringar som var synbara för andra medförde att kvinnorna beskrev att de kände sig bemötta på ett annorlunda sätt. Detta kan ses som ett uttryck för att kvinnorna levde med en hotad värdighet samtidigt som det finns en kamp för att skydda den egna värdigheten. För att skydda sin värdighet strävade kvinnorna med MS efter att bibehålla styrka och kraft i vardagen. De beskrev att kroppen kändes oförutsägbar vilket starkt påverkade vardagen.

Kvinnorna beskrev skrämmande och ovanliga kroppsliga förnimmelser vilka innebar att det kändes svårt för dem att förstå vad som höll på att hånda med den egna kroppen. Kvinnorna med MS beskrev en känsla av förlust av kroppslig kontroll och tillit till den egna personen. Att planera vardagen var viktigt men samtidigt så beskrev kvinnorna att det var svårt eftersom att kroppen inte längre

I kvinnornas dagliga liv fanns också en strävan efter att bibehålla kraft där hotet från sjukdomen inte accepterades och där kvinnorna beskrev att de vägrade att låta sjukdomen ta kontroll. Att få vishet om framtiden var mycket viktigt och kvinnorna uttryckte en önskan om att bli bemötta med ärlighet. Kvinnorna med MS undrade varför just de drabbats och många gånger kände de sig övergivna med obesvarade frågor, vilket ledde till att de sökte information på egen hand. Känslan av att vara en stark person gjorde det möjligt att leva med sjukdomen och familjen var en stark kraft i kvinnornas vardag där de kämpade för barnens skull. Att kämpa för familjen och inte ge upp beskrevs som att inte vilja överge familjen som i sin tur fanns där för kvinnorna. Att möta andra med MS innebar att kvinnorna inte kände sig annorlunda samtidigt som individuella behov uppmärksammas. De fokuserade på det som var möjligt att genomföra i det dagliga livet och att ta det i sin egen takt gjorde att det var möjligt att utföra saker i vardagen. För att kunna vara delaktiga i det dagliga livet valde kvinnorna att be andra om hjälp och de hoppades på lindring och bot.

I delstudie II beskrivs innebörden av fatigue (extrem trötthet relaterad till MS) 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 känna sig frånvarande och tudelad 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. För kvinnorna verkade fatigue
medföra att kroppen, istället för att fungera som ett verktyg för att klara av
vardagen, blivit en fiende. För kvinnor med MS tolkades upplevelsen av 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 beskrevs som en upplevelse som omfattade hela kroppen. Det
var nödvändigt att låta händer och armar hänga ner och förmågan att hålla den
egna kroppen upprätt saknades. De muskler som egentligen skulle hålla upp
kroppen kändes försvagade och känslan av att ha flera ton av sandsäckar knutna
kring benen beskrevs. Där fanns en känsla av att vara styrat av den egna kroppen
och att inte kunna klara sig. Att ta beslut och utföra vardagliga saker på samma
sätt som tidigare var inte längre möjligt. Vardagliga göromål väckte känslan av
fatigue samtidigt som denna känsla också kom över kvinnorna efter att de inte
gjort någonting. Trots detta fanns en stark önskan om att vara aktiv och leva som
tidigare.

Känslor av osäkerhet och oro uttrycktes och kvinnorna kände sig opålitliga då de
inte kunde hålla löften de givit till andra. Det var svårt för hela familjen och
kvinnorna beskriv att också familjen led. Att beskriva fatigue var svårt för
kvinnorna och för andra var denna känsla en omöjlighet att förstå. Fatigue
beskrevs som en osynlig känsla som fanns inom kvinnorna och den syntes inte
utanpå. Upplevelsen av fatigue skiljde sig avsevärt från den känsla av trötthet
kvinnorna hade upplevt som friska. Att inte kunna klara sig själv och behöva
hjälp av andra ledde till att kvinnorna kände sig som en börda. Kvinnorna var
tvungna att hushålla med krafterna, vilket också var svårt då de förlorade energi
utan att göra något alls. Känslan av fatigue var alltid närvarande och den varken
försann eller lättade efter vila eller sömn, trots detta hoppades kvinnorna på att
vila kunde ge dem lindring.
Känslan av en annorlunda frånvaro var relaterad till en ovanlig och osynlig känsla samt känslan av att vara frånvarande. Fatigue beskrevs 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 kändes inte klar och där fanns en känsla av att ha blivit 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 de kände sig frånvarande. Kvinnorna beskrev en känsla av att vara tudelad, där en del deltog medan den andra delen iakttog.

beskrev hur de mådde bra när de mötte andra med liknande erfarenheter av att vara sjuk samt genom en djup och nära relation till familjen.

I delstudie IV beskrivs innebörder av bemötande för kvinnor med MS. Denna studie föreslår att innebörder av bemötande för kvinnor med MS består av två samtidigt existerande dimensioner där bemötande från andra kan betyda att känna sig bekräftad av andra och att samtidigt sakna bekräftelse av andra. Kvinnor med MS upplevde bekräftelse genom att känna sig förstådd av andra, och som kontrast innebar känslan av att vara ifrågasatt och att bli bemött med bristande förståelse att kvinnorna saknade bekräftelse. Bemötande för kvinnor med MS kan förstås som att uppleva sig som en värdefull person och att samtidigt uppleva sig förminskad. Att känna sig som en värdefull person var relaterat till att bli sett för den du är och att få hjälp utan att ge förklaring. Kvinnorna med MS uttryckte känslor av att vara välkommen att delta som en person som inte var annorlunda från andra. Det kändes bra att bli bemött av andra på samma sätt som de blivit bemötta när de var friska. Istället för att vara uttittade kände kvinnorna sig välkomnade av andra. Att känna sig behövd av andra innebar en känsla av att växa som person och i möten med andra med liknande erfarenhet kände sig kvinnorna förstådda. Att bli tilltalad och igenkänd av hälso- och sjukvårdspersonal innebar att känna sig synliggjord och att känna sig välkommen som en individ. De beskrev att de inte ständigt behövde förklara för hemsjälvpersonal hur de ville att hjälpen i vardagen skulle genomföras.

Samtidigt som kvinnorna upplevde bekräftelse var också känslan av att sakna bekräftelse och förståelse framträdande i kvinnornas vardag. Kvinnorna beskrev att de blev bemötta på ett annorlunda sätt än när de var friska och de kände att andra inte förstod dem. De saknade förståelse från andra personer i sin omgivning eftersom att sjukdomen, med dess utmattning och smärtan var osynlig. Andra personer såg dem som en sjuk person med synbara kroppliga problem och de
kände de att andra tyckte synd som dem. Kvinnor med MS beskrev en känsla av att inte vara välkommen och att det sakandes plats för dem i det friska samhället. Skillnaden mellan att kunna gå och att sitta ner i rullstol var slående för kvinnorna och de beskrev att de blev ignorerade och bemötta med hänsynslöshet. Kvinnorna beskrev att ingen brydde sig om deras upplevelser och de hela tiden var tvungna att förklara sina behov i vardagen. Råd från hemtjänstpersonal kändes överflödiga och kvinnorna beskrev att de kände sig som en börda för hemtjänstpersonal som var stressade av deras behov i vardagen. Kvinnorna beskrev att det var svårt att förklara sina personliga behov och de kände att behov i vardagen var underskattade, vilket de relaterade till sjukdomens oförutsägbarhet.

Denna doktorsavhandling föreslår att innebörden av kvinnors upplevelse av att leva med MS kan förstås bestå av en rörelse mellan de två dimensionerna; att ha ett värde (I, III, IV) och att känna sig obetydlig inför andra (I, II, IV). Kvinnor med MS strävar efter att skydda en hotad värdighet samtidigt som de känner sig exkluderade av andra. Känslor av välbefinnande framträder i dimensionen av att ha ett värde medan dimensionen av att känna sig betydlig inför andra innebär ett lidande i kvinnornas dagliga liv. Trots att dessa två dimensioner skiljer sig till innehåll, kan de inte ses som varandras motsatser. Istället existerar dessa två dimensioner samtidigt (I-IV).

Kunskap om hur kvinnor med MS förstår sitt dagliga liv ger ökade möjligheter att formulera vård och omvårdnad utifrån individuella behov och förväntningar. Att rikta uppmärksamheten mot kvinnornas upplevelser av förändrade relationer mellan kroppen, jaget och omgivningen är nödvändigt för att kunna identifiera individuella erfarenheter hos kvinnors som lever med MS. Denna doktorsavhandling ger ny kunskap genom att visa att innebörden av kvinnors upplevelser av att leva med MS kan förstås som en strävan efter att skydda sin värdighet samtidigt som kvinnorna känner sig exkluderade av andra. Dessa två
dimensioner medför en känsla av att må bra och å andra sidan ett lidande för kvinnorna i deras dagliga liv. För kvinnor med MS innebär detta en rörelse mellan att ha ett värde och känna sig obetydlig inför andra. Kvinnornas känsla av att vara obetydlig inför andra står som kontrast till att betrakta människor som likvärdiga trots skillnader. Motsatsen till att känna sig betraktad som annorlunda och att sakna gemenskap med andra, visar sig då denna avhandling föreslår att en delad förståelse och känslan av att vara värdefull har betydelse för att kvinnor med MS kan må bra och uppleva värdighet i det dagligalivet.
ACKNOWLEDGEMENTS

This study was supported by the Department of Health Science, Luleå University of Technology, Luleå, Sweden.

My sincerest gratitude to the women who generously participated in this study.

I would first and foremost like to thank my main supervisor, Professor Siv Söderberg, Head of the Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden, for excellent and sharp supervision, for being most supportive and for being more than generous in sharing your extensive knowledge throughout this thesis work.

My co-supervisor, Associate Professor Lisa Skär, Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden, for being supportive, and for criticism and constructive advice.

Fellow PhD students and colleagues in the Division of Nursing and at the Department of Health Science, Luleå University of Technology, Luleå, Sweden, for your support, and for interesting and valuable discussions.

My dear friends, and especially Kristin Ek, Lisa Larsson, Anna Johansson, Sara Hollén, Helena Lantto and Linda Sundqvist for friendship, and for never being far away. Wow and hearts☺.

My dear family, Axel, Astrid, Per, and last but not least, dad, for love and invaluable support.
REFERENCES


protective processes in the lives of people with chronic disabilities. *Qualitative Health Research, 13*, 184-206.


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.


The Meaning of Women’s Experiences of Living With Multiple Sclerosis

MALIN OLSSON
Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden

JAN LEXELL
Division of Medical Science, Department of Health Science, Luleå University of Technology, Luleå, Sweden

Department of Rehabilitation, Lund University Hospital, Lund, Sweden

SIV SÖDERBERG
Division of Nursing, Department of Health Science, Luleå University of Technology, Luleå, Sweden

We conducted a qualitative inquiry in order to describe the meaning of women’s experiences of living with multiple sclerosis (MS). Multiple sclerosis is a chronic autoimmune disease of the central nervous system. The majority of persons living with MS are women. Living with MS has been described as difficult because of the uncertainty of the illness. Ten women with MS were interviewed 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.

Received 24 July 2006; accepted 18 July 2007.

We are grateful to the women who kindly volunteered to participate in the study and to Eva Månsson, ROT, MSc, for assistance in recruiting participants. We also are grateful for the support received from the Department of Health Science, Luleå University of Technology, Lulea, Sweden.

Address to Malin Olsson, Division of Nursing, Department of Health Science, Lulea University of Technology, SE-97187, Lulea, Sweden. E-mail: Malin.Olsson@ltu.se
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 & Confraveux, 2001). The symptoms have a strong impact on people’s bodily functions, daily activities (e.g., Hunyi & Nanayakkara, 2001; Månsso & Lexell, 2004; Steinman, 2001), and subjective experiences of the illness (e.g., Flensner, Ek, & Söderhamn, 2003; Koch & Kelly, 1999b; Koopman & Schweitzer, 1999; Olsson, Lexell, & Söderberg, 2005; Yorkston, Klasner, & Swanson, 2001).

Multiple Sclerosis (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 often is perceived as hard due to uncertainty and lack of control.

Koch and Kelly (1999a) reported that women with MS are faced with several losses in daily life, and to cope with the illness women with MS often are forced to make changes in their lifestyle. These changes are described as a movement from being healthy and free to a dependency on others in daily living. Kralik and colleagues (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) pointed 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 (Grigger, 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 that, 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, our aim in 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 to 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 audiotaped 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

As our aim was to describe the meaning of women’s experiences of living with MS, a phenomenological hermeneutic interpretation was chosen to analyze the transcribed interviews (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). Using this method, we made attempts 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 then are organized into subthemes and themes, with an aim to explain the text.

Developed by and supported from the naïve reading, the structural analysis, our preunderstanding, 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 preunderstandings 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 seemed,
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>
</tr>
</thead>
<tbody>
<tr>
<td>An unrecognizable body</td>
<td>Being directed by the ill body</td>
</tr>
<tr>
<td></td>
<td>Having the will but finding it troublesome to perform</td>
</tr>
<tr>
<td></td>
<td>A feeling of being perceived as different</td>
</tr>
<tr>
<td>Trying to maintain power</td>
<td>Seeking answers to unpredictability</td>
</tr>
<tr>
<td></td>
<td>Having the strength to fight</td>
</tr>
<tr>
<td></td>
<td>Seeing possibilities in life</td>
</tr>
</tbody>
</table>

out of reach. The no-longer-working body was filled with new sensations such as fatigue, weakness, stiffness, and unsteadiness. To receive 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 a 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 exhausted, 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 worked 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 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, and 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 also were 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 for 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 reason 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 it, 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 their dignity, a struggle is evident. To keep safe from harm and to protect their 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) described two dimensions of human dignity, where one dimension is seen as a constant and the other is viewed as 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) claimed 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) showed 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 one’s life. When the illness developed, the women with MS felt fear because they did not know what was happening to their bodies. Frank (1995) 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) described 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 in 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 is significant to the state of living with an illness. Charmaz (1983)
stated that living with a chronic illness implies feelings of living a restricted daily life and also a loss of the former self-image.

Women with MS felt fear because they did not know how the future would turn out. Toombs (1992) described 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) described 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. Charmaz (1983) showed that people living with chronic illness often felt like they were a burden to others, and this feeling had impact on their self-image. 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 like
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) described 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 (1959/1993) 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. By exploring personal boundaries people living with chronic illness strive to reconfigure their daily lives (Kralik, Koch, Price, & Howard, 2004). According to Corbin and Strauss (1987) and Charmaz (2006), people living with chronic illness strive to include the illness in their daily lives and identity.

According to Buber (1923/1994), human life always is 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) stressed 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, 1923/1994). 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 and colleagues (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) emphasized 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.

Since our interpretation of the findings in this study is based on existential philosophy, we suggest an existentialistic understanding of the meaning of women’s experiences of living with MS. The core feature of the existential philosophy used for the understanding of the findings is that people, despite outer circumstances, have influence on their own lives. The assumption is also that people live related to others, and that relation is of importance. 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 what 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


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
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 can 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 (Bethoux et al. 2001), whose symptoms include numbness, visual impairment, lack of co-ordination, paralysis, fatigue, sphincter dysfunction and sexual problems (Hunyi & Nanayakkara 2001, Steenman 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 & Jezewski 2001).

We have found no previous research that has addressed the meaning of fatigue as experienced by women with MS. Narratives from these women with multiple sclerosis (MS) 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 (Flemsner 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...
the meaning of a phenomenon by interpreting narrative interviews fixed as a text. To gain understanding about a text it is important to follow the dialectic movement between the event and the meaning, understanding the whole as well as the separate parts. Interpretation is described as a particular form of understanding when applied to the written expressions of life. Interpretative reading can generate a deeper understanding of the phenomena under study, based on a development from explanation to a new understanding. In this new understanding, the text is interpreted based on the researcher’s preunderstanding (Ricoeur 1976). This method has been used previously by, for example, Sundin et al. (2001), Söderberg et al. (1999, 2002) and Öhman et al. (2003).

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.

Data analysis
The interpretation consisted of three phases. The first phase was a naïve understanding of the text in order to gain a sense of the whole. This provided ideas for the next phase, which was the structural analysis. During the structural analysis the text was divided into meaning units, with sentences linked to each other by content. The meaning units were then organized into subthemes and themes based on differences and similarities in meaning. During the third phase, the text was interpreted as a whole, resulting in a comprehensive understanding developed from and supported by the naïve understanding, the structural analysis and our preunderstanding (cf. Ricoeur 1976). Our preunderstanding was based on our experiences as nurses and as a physician working with people with chronic illnesses, and as researchers in this area. We made ourselves aware of our preunderstanding and interpreted the interview text as open-mindedly as possible.

Findings
Naïve 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 life 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 as 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 lots 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:

They lose 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.

Table 1: Themes and five subthemes in the findings

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiencing the body as a barrier</td>
<td>A feeling of having a heavy body</td>
</tr>
<tr>
<td></td>
<td>A feeling of the will but not the ability</td>
</tr>
<tr>
<td>Experiencing a different absence</td>
<td>An unusual and invisible feeling</td>
</tr>
<tr>
<td></td>
<td>A feeling of being absent</td>
</tr>
</tbody>
</table>

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 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 1993). The body for women with MS in this study is interpreted as a barrier in daily life, and the body cannot be taken for granted. This is in line with the findings of Flensner et al. (2003), who described fatigue among people with MS as something that was perceived in the body, with an increased awareness of the body the whole time.

The feeling of having a heavy body was 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. When the body no longer serves a person, as in the case with women who have MS, it becomes a visible obstacle which hinders the person’s presumption of having power over themselves.

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 Söderberg 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 life 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 change 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 Flensner 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 (Söderberg 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...
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 life and it enables people to overcome difficult situations. Morse and Penrod (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. 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.
Acknowledgements
We are grateful to the participants and to Eva Månsson for assistance in recruiting participants.

References


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


Meanings of feeling well for women with multiple sclerosis

Malin Olsson, Lisa Skår, Siv Söderberg

Division of Nursing, Department of Health Science,
Luleå University of Technology, Luleå Sweden

Corresponding Author

Malin Olsson Division of Nursing, Department of Health Science, Luleå University of Technology, SE-97187
Luleå, email: Malin.Olsson@ltu.se

Acknowledgements

We are grateful to the women who kindly volunteered to participate in the study
Abstract
In research concerning multiple sclerosis the factors which impact on people’s well-being and quality of life have been studied, but little has been written about what it means to feel well for women with MS. Therefore, in this study our aim was to describe meanings of feeling well for women with MS. We interviewed 15 women with MS and a phenomenological hermeneutic interpretation was practised to analyze the interviews. Through this study it can be understood that finding a pace where daily life goes on means that women with MS feel well when the illness is kept in check and is not the dominant experience. The findings of this study can be used in order to confirm women’s experiences of feeling well, despite living with the consequences of MS. Health care professionals can find the findings of this study useful when they reflect over and formulate the care of women with MS when attempting to support the latter’s desire to feel well in their daily lives.

Key words
health; hermeneutics; lived experience; multiple sclerosis (MS); nursing, phenomenology; women’s health
Chronic illness means disruptions and alterations in life (Bury, 1982; Charmaz, 1983, 1987; Curtin & Lubkin, 1998; Morse, 1997) and might alter the very foundation of life as the illness implies a new and different life condition (Bury, 1982). There is quite extensive knowledge available concerning living with chronic illness and its impact on daily life. Toombs (1992) stated that the experience of illness means that the taken-for-grantedness of daily life is interrupted and that a fundamental loss of wholeness manifests itself in different ways. In contrast, there is little known about what makes people feel well despite chronic illness. However, Jumisko, Lexell and Söderberg’s research (2009) shows that people living with a traumatic brain injury (TBI) describe that when the unfamiliar life with TBI become familiar they experience feeling well. Similar to this, Alsker, Bongaardt and Josephsson (2010) pointed out that women with chronic rheumatic conditions strive to find a good everyday life despite being ill.

Multiple sclerosis is a chronic autoimmune disease with a well known impact on everyday life (Courts, Buchanan & Werstlein, 2004; Olsson, Lexell & Söderberg, 2005; Olsson, Lexell & Söderberg, 2008; Yorkston, Klasner & Swanson, 2001). The majority of people living with MS are women and the illness usually shows its first symptoms between the ages of 20-40 years and, next to accidents, is the most common neurological disability among young adults (Vukusic & Confavreux, 2001). Research concerning MS is quite extensive and the effects the illness has on people’s lives are obvious. The areas explored have mainly concentrated on psychosocial factors, adaptation, social support, self-efficacy, coping, physical disability and quality of life (Feinstein, 2004; Finger, 1998; Kirkpatrick Pinson, Ottens & Fisher, 2010; Mitchell, Benito-Léon, Morales Gonzáles & Riviera-Navarro, 2005; Sprangers, de Regt & Andries, 2000). A shift in research focus is needed if more knowledge is to be gained about how it is to feel well when living with MS.

Research (Devins, Edworthy, Seland, Klein, Paul & Mandin, 1993; Sprangers et al., 2000) has shown that people living with MS have a lower quality of life than those living with other chronic illnesses because the effect of MS on daily life is greater. According to Reynolds and Prior (2003) women living with MS use strategies to achieve a quality of life that involves constant negotiation, as negative and positive forces are in competition. Aronson (1997) and Pfennings et al. (1999) have shown that the progression of the illness and the resultant decline in body function has a negative impact on the quality of life. Uncertainty, discrimination, problems in accessing public places and economic difficulties were factors which engendered a constant struggle. Despite these debilitating factors, women with MS still strive for well-being. Setting personal goals, maintaining valuable roles, trying out different ways of living in order to keep up with interests and maintaining

...
relationships and contacts with other people, were seen as positive forces in life and these were also considered as a way in which to experience well-being (Dyck, 1995; Reynolds & Prior, 2003).

According to Brunet, Hopman, Singer, Edgar and McKenzie (1996) women with MS seemed to cope with the illness better than men, a finding that contrasted with Miller and Dishon’s research (2006) which found that women experience a lower life quality than men. Studies (Amato et al., 2001; McCabe & De Judicibus, 2005; Miller & Dishon, 2006) show that occupational conditions, changes in economic circumstances, depression, fatigue and disabilities are factors which affect life quality among people with MS. Medical treatment for depression and coping with stress tends to improve the quality of life among people suffering from MS (Hart, Fonareva, Merluzzi & Mohr, 2006; Sutherland, Andersen & Morris, 2005). Studies (Brunet et al., 1996; Forbes, While, Mathes & Griffiths, 2006; Miller & Dishon, 2006) call attention to the problems of measuring well-being and advocate research that focuses distinctly on expressing people’s personal experiences. Fawcett and Lucas (2006) noted the importance of a healthcare based on individual needs and Toombs (2004) states that knowledge concerning personal experience is a de facto prerequisite for supporting well-being among people with MS.

In summary, the literature review shows that research concerning wellbeing has a mainly quantitative approach (i.e., with focus on quality of life) and findings points to problems in daily life but that people with MS still strive to experience well-being. There is a gap in available knowledge, as the question of meanings of feeling well for women with MS is not touched on. Factors which impact on well-being are both identified and well known, but little has been written about meanings of feeling well despite living with MS. As a result, the chances of meeting the needs of women with MS and supporting their experiences of feeling well are limited. Thus, the aim of our study was to describe meanings of feeling well for women with MS.

Method

Participants and Procedure

Fifteen women diagnosed with secondary progressive MS participated in the study. The criteria for participation were adult women, with a secondary progressive type of MS, and that their daily life was influenced by the illness. The women’s ages ranged from 35 to 70 years (median: 54 years) and they had experienced symptoms for about 12 to 37 years (median: 32 years). The time elapsed since diagnosis varied from 7 to 34 years (median: 24 years). Eight women were married, three were cohabiting and four were single. Ten women were receiving disability pension, three a state pension and two were working part-time. All of the
women were in need of mobility aids or special equipment. The women’s participation was arranged through a hospital in northern Sweden. At the hospital, a registered nurse contacted the women, informed them about the study and invited them to participate. To give further information and in order to obtain informed consent, a letter was sent to the women. This letter included information about the study and a reply form where informed consent of participation could be given. After they had agreed to 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). All the women preferred to be interviewed in their own home. The women were asked to talk about experiences of feeling well and treatment in daily life. The meanings of treatment will be reported elsewhere. Questions were asked to clarify their experiences. The interviews lasted for between 40 and 60 minutes and were transcribed verbatim. Data collection was performed during 2007.

Ethical Considerations

All of the women gave their informed consent both verbally and in writing. Approval of the study was given by the Regional Ethics Review Board. The participants were guaranteed confidentiality and anonymous presentation of any findings.

The Phenomenological Hermeneutic Interpretation

As our aim was to describe meanings of women’s experiences of living with MS, a phenomenological hermeneutic interpretation was chosen for analysis of the transcribed interviews (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). In using this method, attempts are made to explain and, from there, understand meanings of a phenomenon through the interpretation of narratives. In order to gain understanding, it is necessary to constantly move between the text as a whole and its parts. When applied to life expressions as a text this method implies an interpretation as a certain form of understanding. 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.

The phenomenological hermeneutic interpretation in this study consisted of three interrelated phases. In the first phase we started the interpretation with a naïve reading of the text in order to gain a sense of its whole. The naïve understanding provided ideas for the next phase, the structural analysis. The aim of the structural analysis was to identify and explain parts of, and patterns in, the text and validate or invalidate the naïve understanding. In the structural analysis the text was divided into meaning units. The meaning units were then
condensed into formulated meaning units. The formulated meaning units were grouped together by similarities and difference in meaning. Based on similarities and differences the formulated meaning units then were abstracted into subthemes and one major theme (cf. Lindseth & Norberg; Ricoeur, 1976). We compared the major theme and subthemes with the naïve understanding in order to achieve validation. Developed from, and supported by, the naïve reading, the structural analysis, our pre-understanding and the literature, the text was interpreted in its totality and resulted in a new comprehensive understanding (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). The interpretation was conducted as open-minded as possible, with an awareness of our pre-understandings as nurses and as researchers in this area.

Findings

Naïve Understanding

The naïve understanding concerning meanings of women’s experiences of feeling well seemed, as a whole, to encompass feelings of searching and also striving for peace and harmony in an everyday life constrained by MS. There were feelings of approaching everyday life just as it is, finding one’s own pace, and wanting to live in the present. Waking up in the morning with a functioning body seemed to be related to wishing to continue with yesterday’s unfinished things. When faced with the facts of MS, there seemed nevertheless to be feelings of wishing to live like healthy people. There were feelings of not giving in, holding on, and using a sense of strength embedded in one’s personality. There was a feeling of peace and silence with no demands from the outside world. At the same time feelings of relaxation were manifested by engagement in the lives of other people. This seemed to be related to feeling important, needed and loved by an understanding family and by others. There seem to be feelings of not wanting to be totally dependent on others and choosing for oneself, as well as feelings of being able to live a life resembling the one they had when healthy, thanks to help from others based on their needs in daily life.

Structural Analysis

The structural analysis resulted in one major theme with five subthemes. The major theme and subthemes are presented in text below and illustrated with quotations from the interviews.

Finding a pace where daily life goes on. The major theme Finding a pace where daily life goes on was constructed from five subthemes: having power to do the ordinary, feeling contented, feeling peace and harmony, feeling needed, and feeling understood.
Having the power to do the ordinary. The women with MS described a good day as being when they could get up in morning and during the day be able to go outside. Having the strength to do ordinary things was of most importance for them, for example having dinner with the family, sitting out on the balcony and getting properly dressed gave rise to feeling well. Women with MS said that when their bodies functioned with some predictability, meaning that they were able to do things which they had not managed the day before they felt open to other people and did not shut themselves away. They felt free when they could manage to do things by themselves with relevant support in daily life. Help from a personal assistant created conditions for living as they did before the illness and meant being one’s own person and not being totally dependent on the family, factors which were important for feeling well.

Waking up in the morning and feeling fairly alert. Well that it feels good to get out of bed. Yes I think that, to have a good start to the day.

It’s the freedom to get around by yourself outside. I have an electric motorbike which makes it possible to get around by myself and I don’t have to wait for the transportation service and to book and order and well you can get inside different stores or anyhow many stores, oh no, I think it’s is good just to get outside. I think it feels good.

Feeling contented. The women with MS described that they no longer fretted themselves over not being able to do ordinary things like before and they did not have a bad conscience about this. They expressed that a lot of things were no longer taken for granted. Women with MS spoke of needing an inner strength to approach daily life. It was vital to encourage oneself and choosing to be strong was described as a source of feeling well. The decision to feel well despite having a body that no longer functioned was expressed as better than struggling to walk until it was unbearable. The women with MS described changing perspectives regarding the life and realizing the essentials. There was a feeling of approaching daily life as it is and learning how to live.

It has to take its time. It takes half a day to get out of bed and I don’t have to stress. I can sit in peace and have breakfast, and just, ok well its four o’clock, but I have been feeling well today, without a bad conscience.

There are quite a lot of things which aren’t a matter of course any more, but it’s hard to identify them, you have got used to the situation, you have as I say got used to the illness, but you never accept it, but
you have to get used to, well not being able to walk anymore and situations like that, and now that you’re used to it you feel quite good.

*Feeling peace and harmony.* Women with MS said that they felt well by taking it slowly and finding an atmosphere of rest, relaxation and being present in the moment. The women described feeling free as being related to stillness and silence. By rejecting acquaintances they felt were too much effort the women said that they could save energy. With no stress and demands from the world around them the women listened to their inner self and their bodies. The women with MS described getting the help needed without constantly having to fight for it and they described feeling well when learning to be clear about and expressing their own needs.

I feel that I just want to be, thus I want to feel well by just being and taking the day as it comes. I feel a great need to sleep and so taking everything in peace and quietness, no stress.

To be in balance and in harmony with oneself and sort of not having too many stressful situations, or demands from the outside world so to speak. You, you have gotten rid of all the musts.

*Feeling needed.* Women with MS said that they realized their significance for their children and they described being involved in their children’s lives. They described helping the children to see the positive aspects of life and passing on the ability to turn hard times around. Experiencing the children’s thankfulness for what they had been given in life was most valuable. The women described how reaching out to other people, giving and helping others made them feel well; they felt valuable by engaging with society and they said that they could do something good for others and support others in need.

He [the son] knew that I was ill, but still he had a lot of friends over and there were always people here, so he has never felt ashamed of my illness and has always been able to have friends over and he has known that I have been there for him and when I had gotten it [MS] when he played sports he said, mum you don’t have to do anything just come and watch the games, sit on the grandstand where I can see you. You don’t have to do anything, if you just sit here on the grandstand and watch me, and then I realized how important I was, just being a spectator was enough.

I sat and talked about how beautiful everything was outside, soon it will be spring and the grass will be green and the flowers will come. I talked about all kinds of things and I talked and then one day I saw a
teardrop running down her cheek and it was like at first I was afraid that I had made her sad, but it was a reaction from her, it was a feeling and then when I sat there, in that moment I realized that everything has a meaning. It wasn’t meant that I should work. I have this illness because I can manage it and help others.

*Feeling understood.* Women with MS described that they felt well through meeting others with similar experiences. When they met others with MS the women found themselves understood and not questioned. They expressed a feeling of honesty and close fellowship. By sharing experiences the women learned about how to go about things in everyday life. By listening to others’ narrations about how to handle daily life the women expressed how they found new insights and solutions. The women with MS described a relationship with their family characterized by closeness and deep understanding. When the family understood why the women did not have enough energy, daily life was eased and the women felt well. The tightly bound family gave the women strength and they experienced vitality from sharing daily life with the family members.

It’s a different understanding and anyone can share their experiences if they have had something similar, but it’s not the same as when someone has the same illness, then it becomes more relevant. They know what they are talking about, or we know what we are talking about.

I have a family who is there for me and who fully understand my illness so they support me. My husband is always involved even in the organization of the assistant. He accompanies me there. He understands that I can’t do much with my hands so he cleans. He has done that all the time and helps me very much and then we have had many common interests.

**Comprehensive Understanding and Reflections**

In this study, our suggestion is that meanings of feeling well for women with MS manifests itself as finding a pace where daily life goes on. Feeling well meant that the women with MS had the power to do the ordinary, they felt contented and they felt peace and harmony. For women with MS feeling needed and feeling understood were central to feeling well despite their illness. Tillich (1961) described how the concept of health only has meaning in relation to an existing threat of illness. Dahlberg, Todres and Galvin (2009) state that the existential understanding of well-being and illness is bound up in the human condition. Being human simultaneously encompasses limitations and possibilities. From this, it becomes clear that it is not fruitful to
consider illness and well-being as separate. Despite living with limitations and hindrances caused by illness, this study shows that women with MS do experience feeling well in everyday life.

According to Gadamer (1996) health does not present itself to us, thus its character is concealed. Despite this concealed character health appears in the form of feeling well and when people feel well the strains in life is held back and health is unobtrusive. In this study it could be understood that finding a pace where daily life goes on means that women with MS feel well when illness is kept in check. By finding a balance in daily life were illness is not the dominant experience women with MS feel well. This could be understood from Gadamer (1996) who claims that when people are healthy everything flows in a rhythmic and balanced manner. Health is a feeling of being in harmony with oneself and it is an inner accord which cannot be measured.

Feeling well for women with MS was strongly related to how the body felt, and feeling well meant having the power to do the ordinary, such as being able to get up in the morning and starting a good day. The women recounted that doing the ordinary was being able just to sit on the balcony, getting properly dressed and to have dinner with the family. According to Dahlberg et al. (2009) health means well-being, that is, being able to live life in a personally desirable way and having the vitality to carry through the essentials of life, such as minor or major life projects. Women with MS felt well when their bodies functioned with some predictability, when they were able to manage and trust themselves in everyday life. According to Merleau-Ponty (1996) it is through the body and bodily experience that the surrounding world becomes meaningful to us. When the body functions in a predictable way it is simultaneously present and absent and the person’s attention is directed towards the surrounding world. For women with MS, feeling well is understood as if the rhythm of the body in some sense is predictable during the course of the day.

The women with MS described getting used to the fact that a lot of things were no longer taken for granted. There was a feeling of approaching daily life as it is and learning how to live. According to Toombs (1995) reclaiming life is possible when one lives with an illness. As living in constant fear is an unbearable feeling, it is possible to reclaim life by deciding to focus on the present and develop strategies for dealing with everyday difficulties. Dahlberg et al. (2009) draw upon Heidegger’s philosophy when they show the experience of letting be, as taking on the circumstances of life and being reconciled to the possibilities available. From this, letting-be-ness means peace as a source of well-being. In their narrations the women with MS said they felt well when they no longer had to wrestle with a bad conscience, when they no longer fretted over not being able to do ordinary things like before. This is in line with Dahlberg et al. (2009) who describe that having a good life means taking on the challenges of illness with stillness. Women with MS expressed a feeling of approaching daily life
as it is and focusing on the essentials in life. They felt well by choosing strength and encouraging oneself. According to Frankl (1993) the essential in life is the specific meaning that people ascribe life in a given moment. From this point of view there is never an unlimited number of choices, but there is always the opportunity to decide how to approach a fixed situation.

The women with MS felt well when they were at home alone, feeling peaceful and released from external demands and they felt harmony through living at their own pace. According to Dahlberg et al. (2009) resting from demanding surroundings and allowing oneself just to be implies well-being through finding stillness. In this way a person can be alone but still not feel lonely. To be alone is thus something positive and chosen; it can also be powerful in that it is calming and brings peace. Chosen loneliness is pleasant and restful, a turning towards yourself in an experience of well-being (Dahlberg, 2007). Tillich (1973) understands being alone as a natural desire for solitude something which can be experienced as a protection and as a victory over isolation. Thus being alone can mean strength and courage in feeling whole and integrated as a person. Feeling that they were listening to themselves and their body meant that the women with MS experienced feeling well. In health, people know their body, they recognize and trust the information which it gives them through the senses. People then use this knowledge in order to protect and care for their body (Corbin, 2003).

Feeling needed by others meant that the women could realize their value and they felt well when they reached out and could help another fellow being. According to Frank (2004) the will to give to others, means taking an active role in order to regain the relationship with oneself and the world. When one experiences the needs of others as one’s own, the relationship between the world and oneself is reformulated, and there exists peaceful living in a way that feels right. Feeling well was interpreted as feeling understood and the women with MS described how they felt well when they met others with similar experiences. Frank (2004) has described the fellowship among people who live with illness as a sense of belonging and a mutual understanding of what it is to live; this is because people living with an illness have learnt by experience what it is like to live with pain or anguish.

The women with MS described their relationship with the family as close and based on a deep understanding. By sharing the family’s life their own daily life was eased and the women felt well. Olsson et al. (2008) showed that for women with MS, the family is a strong source of power in their daily lives, and despite being ill, women with MS experience dignity. According to Jumisko et al. (2009) being loved and being given confirmation is a source of feeling well for people with TBI. Marcel (1963) argues that the experience of being welcomed by others formulates human dignity, and people’s experiences of health is not to be seen as a
condition which one feels introspectively; rather it is being involved in the world and being with others (Gadamer, 1996).

Limitations and Strengths

Preunderstanding needs to be visualized and taken into account. In the interpretive tradition, openness when approaching a text is inherent as a goal and at the same time, the preunderstanding also undeniably directs the researcher (Wiklund, Lindholm & Lindström, 2002). According to Dahlberg and Dahlberg (2003) preunderstanding cannot be cut off, but the intentional threads which guide human understanding ought to be slackened. In order to allow an understanding of a phenomenon as it is, bridling is used to read the codes presented by the phenomenon. In this study, the interpretation was carried out from the perspective of our experience and understanding of women with MS as nurses and researchers in nursing science. The interpretation we present in this study is the one we found the most probable. According to Ricoeur (1976), there is always more than one way to interpret a text. In this study, possible interpretations have been considered and compared (cf. Lindseth & Norberg, 2004) in critical discussions with peers (cf. Ricoeur, 1976). The proposal of this study presents one way to understand meanings of feeling well for women with MS. Our goal has been to find possible meanings and the findings can be plausible to similar situations (cf. Ricoeur, 1976).

Conclusion

In conclusion, this study shows that it is possible for women with MS to feel well despite living with illness. The findings of this study can be used in order to confirm women’s experiences of finding a pace where daily life goes on. Health care professionals can use the findings of this study when they reflect over, and formulate the care of women with MS in order to support the latter’s sense of feeling well in daily life. In order to strengthen the wellbeing of women with MS, it is important to focus on what it is that makes women with MS feel well despite being ill.
References


Meanings of treatment for women with multiple sclerosis

Malin Olsson, Lisa Skär and Siv Söderberg
Division of Nursing, Department of Health Science,
Luleå University of Technology, Luleå, Sweden

Correspondence concerning this article should be addressed to Malin Olsson, Division of Nursing, Department of Health Science, Luleå University of Technology, SE-97187 Luleå, Phone+46 920 491000, email: Malin.Olsson@ltu.se

Acknowledgements
We are grateful to the women who kindly volunteered to participate in the study, and for the support received from the Department of Health Science, Luleå University of Technology, Luleå, Sweden.
Abstract

Purpose. The aim of this study was to describe meanings of treatment from others as experienced by women with multiple sclerosis (MS).

Method. Fifteen women with the secondary progressive type of MS were interviewed. The interviews were analyzed with a phenomenological hermeneutic interpretation.

Results. The findings were presented in two themes: experiencing oneself as a valuable person and experiencing oneself as diminished. Meanings of treatment for women with MS can be understood as containing two concurrently dimensions were treatment from others can mean recognizing one self through confirmation as well as being ignored due to missing togetherness with others.

Conclusions. The need to support women’s experiences of being confirmed is in this study obvious. Authorities, the municipality, homecare and healthcare officials as well as personnel ought to consider these findings, in their support of strengthening women with MS in accordance with their needs in daily life.

Key words: interviews, lived experience, multiple sclerosis, nursing, treatment, women
Introduction

Chronic illness has been shown to have a considerable impact upon people’s daily lives. Living with chronic illness restricts people’s daily life and it causes loneliness and feelings of being excluded by others [1-3]. Illness is a most subjective experience and the meaning that people give their experience is embedded in the illness experience itself. Bodily dysfunction disrupts a person’s engagement in the world and illness affects the habitual way of being in the world [4]. Multiple sclerosis is an autoimmune inflammatory demyelinating illness of the central nervous system. It is the leading cause of disability in young adults, with an unpredictable and variable course [5]. Studies [4,6,7,8] have shown the changes in daily life affecting people who live with MS and how meeting expectations from one self and others is not always considered to be a matter of course.

As a result of the imperfectly functioning body, women with MS experience themselves as being met and treated differently by people, whereas, the experience of MS-related fatigue was described as being invisible to others and aroused a feeling of not being understood by others [6,7]. When exploring the stigma that people with multiple sclerosis experience in social relations, Grytten and Måseide [9] showed that people with MS felt ignored or, conversely, experienced people overemphasising the illness during social interaction. People with MS describe the time before an established diagnosis as a time of suffering, where they have been experiencing both a lack of credibility from others and been dismissed as hypochondriacs by healthcare personnel. They have described experiences of not being listened to and having to struggle alone against the illness, after the establishment of a diagnosis, people with MS describe a constant struggle to maintain a daily life which resembles the life they led when healthy [10].

Studies [4,10,11,12] have shown that since problems in daily life vary strongly, people with MS experience a lack of relevant help in contacts with healthcare personnel,
as well as having their emotional needs ignored. According to Abma, Oeseburg, Widdershoven, Goldsteen and Verkerk [13] and Koch and Kelly [14] women with MS found themselves being met with insufficient knowledge about their individual needs, as well as lacking space to express grief and vulnerability when meeting healthcare personnel. Although there seem to be a lack of studies which specifically focus on the experience of treatment for women with MS, such experiences have been studied in other contexts. For example, people living with a traumatic brain injury (TBI) and their close relatives have described how treatment from other people implies being excluded and missing confirmation. People with TBI, and their close relatives, longed for the right kind of help and they appreciated people who tried to understand them [15].

In short, there are, to the best of our knowledge, no studies which focus specifically on meanings of treatment from other people as experienced by women with MS. It is known that people living with MS frequently express resentment that they are denied space to express personal experiences and they believe that they are often met by individuals who lack knowledge about individual needs. What is also salient is the experience of being misunderstood by others, and as consequence their daily needs are not being sufficiently met. Therefore, in order to gain more knowledge, the aim of this study was to describe meanings of treatment for women with MS.

Method

Participants and Procedure

Fifteen women diagnosed with secondary progressive MS participated in the study. The criteria for participation was that they were adult women, with a secondary progressive type of MS, and that their daily life was influenced by MS. The women’s ages ranged from between 35 to 70 years (md: 54 years) and they had experienced symptoms
for about 12 to 37 years (md: 32 years). The time after diagnosis varied from 7 to 34 years (md: 24 years). Eight women were married, three were cohabiting and four of the women were single. Ten of the women were receiving disability pension, three a state pension and two were working part-time. All of the women were in need of mobility aids or special equipment. The women’s participation was arranged through a hospital in the northern Sweden. At the hospital, a registered nurse contacted the women and informed them about the study and invited them to participate. To give further information and in order to obtain informed consent, a letter was sent to the women. After they had agreed to 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. [16,17]). All of the women preferred to be interviewed in their home. The women were asked to talk about experiences of treatment and feeling well in daily life. Meanings of feeling well will be reported elsewhere. 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 2007.

Ethical Considerations

Approval for performing the study was given by the Regional Ethical Review Board (Dnr 07-006M). The participants were guaranteed confidentiality and an anonymous presentation of findings.

The Phenomenological Hermeneutic Interpretation

As our aim was to describe meanings of treatment for women with MS, a phenomenological hermeneutic interpretation was chosen to analyze the transcribed interviews (cf. [18,19]). Using this method, attempts are made to explain and, from there, understand the meaning of a phenomenon by the interpretation of narratives. To gain
understanding, a constant movement between the text as a whole and 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.

The phenomenological-hermeneutic interpretation in this study consisted of three interrelated phases. In the first phase we started the interpretation with a naïve reading of the text in order to gain a sense of its whole. The naïve understanding provided ideas for the next phase, the structural analysis. The aim of the structural analysis was to identify and explain parts of, and patterns in, the text and validate or invalidate the naïve understanding. In the structural analysis, the text was divided into meaning units. These units of meaning were then condensed into formulated equivalents. These formulated units of meaning were grouped together according to similarities and differences in meaning. Based on such similarities and differences, the formulated units of meaning then were abstracted into seven subthemes and two themes (cf. [18,19]). We compared the themes and subthemes with the naïve understanding for the purpose of validation. Developed from, and supported by, the naïve reading, the structural analysis, our pre-understanding and the literature, the text was interpreted in its totality, which resulted in a new comprehensive understanding (cf. [18,19]). The interpretation was conducted in as open-minded a manner as possible, with an awareness of our pre-understandings as nurses and as researchers in this area.
Findings

Naive Understanding

Meanings of treatment from others as experienced by women with MS seemed to encompass a feeling of being viewed as not having the same value as others. When meeting others, the women could feel excluded. The women seemed to feel patronised and there were feelings of being questioned, diminished and disappointed. Being left without adequate help seemed to give rise to feelings of not being safe in daily life. Women with MS seemed to lack the opportunity to make themselves heard and being governed by society was perceived. As a contrast to being met in an excluding manner there were alternative feelings of being understood and taken seriously by others. Being treated in a manner that was no different from how they were treated when healthy was important and when sharing experiences with others who lived with MS, the women’s feelings of being treated differently did not exist. When the women felt that they met people who really could listen to them and their needs in daily life they experienced relief, and seemed to find strength by being understood in accordance with their own outlook regarding their needs in daily life.

Structural Analysis

The structural analysis resulted in two themes and seven subthemes (Table 1). One theme shows the positive aspects and the other reveals the negative aspects of meanings of treatment for women with MS. The themes and subthemes are presented in text below and illustrated with quotations from the interviews.

Experiencing oneself as a valuable person

The theme was constructed from the following subthemes:

Being seen for whom you are. Women with MS said that it felt good to be treated by others in the same way as they had been treated when healthy. Instead of being stared
at, the women with MS expressed how they felt welcomed by others. The women explained that being needed meant growing as a person as well as getting some appreciation for achievements and feeling valuable through recognition from others. The women with MS said that they were believed by the authorities and they did not experience themselves as being questioned by other people. When meeting others who were in the same situation, there was a certain understanding and the feeling of being pitied for was non-existent.

There was this stairway . . . and then they said . . . but how are you going to get up . . . well I will get up but how do I get down . . . well then it is just that two of us will follow you down . . . and then I really felt that despite my illness I was welcomed to come along . . . and that means quite a lot

They do not have to question . . . they do not question why I walk while they sit in a wheelchair . . . or how you manage to carry a tray . . . there no one asks me that . . . they understand what it is all about . . . and they know

*Getting help without giving explanation.* Women with MS narrated meeting healthcare personnel who were striving to provide the best possible treatment. In situations where healthcare personnel approached the women and recognized them, they felt visible and welcomed as an individual. The women described that they did not have to present constant explanations about how they wanted help in daily life and they sensed that it was uncomplicated for the healthcare personnel to assist another fellow human being with their personal needs. Women with MS narrated how they felt understood when meeting healthcare personnel they had met before. Feeling listened to meant relief and the
women with MS explained how they were being taken seriously by healthcare personnel who understood the gravity of the situation. The women with MS said that they had the space to express how their daily life took form and they could share problems previously considered private.

You can sense it . . . and it may depend a lot on the person . . . and . . . but they listen to you . . . you feel that they . . . it is that they listen and they hear . . . in order for me to feel well . . . they want to do the best they can for me . . . because it is me it is about

It is nice thinking people . . . who treat me with respect . . . and it is often a great difference considering this that you can tell if they have close relatives who have the experience of . . . to see a person be ill . . . vulnerable

**Experiencing oneself as diminished**

The theme was constructed from the following subthemes:

*Getting unwanted attention.* Women with MS described that they were being treated differently than from the time when they were healthy. Sometimes they experienced that they were treated as a child and they believed that others did not understand them. They felt that their exhaustion and pain were not visible to others since such feelings did not show on the outside, and paradoxically, the women said that others viewed them as ill and someone to view with pity. The women with MS said that the feeling of being pitied for increased their feeling of being ill. When meeting other people, even those who were well aware that the women had MS, they still felt that others did not show sufficient understanding. The women with MS described trying to explain their
longing to live in the same way as when healthy, but they felt that others did not want to talk about the illness and did not understand their yearning to live as before.

It doesn’t show on the outside . . . still you feel really ill . . . it is almost as if you want to shout . . . can’t you see how ill I feel . . . if I just could get it little in one leg . . . little . . . little you almost do not dare to think it [so it would show on the outside]

It is like you become even more ill . . . if it hadn’t been for this damn tiredness . . .

I really do not feel particularly ill . . . and haven’t felt that during this whole time . . . but of course if someone comes and says oh little friend come here and sit down and rest and . . . well oh . . . I might be even more ill than I believe . . . I might be really really ill

_Lacking value from not feeling like a regular person._ Women with MS felt as though they were a burden to society and described a sensation of not being welcomed. They felt excluded and they believed that there was no room for them in a healthy society. The women claimed that they did not have the opportunity to make themselves heard and when going out in public they felt they were being shut out of public places. The difference between being able to walk and sitting in a wheelchair was striking and they expressed experiences of not only being ignored, but also met by others in a ruthless way. These women described the contact with authorities as time consuming and they felt exhausted by having to comply with routines that consumed their strength and energy.
We people who live with incurable illness . . . we have no opportunity to choose away our situation . . . and still the pension decreases when we haven’t even gotten up to something and in the meantime the cost for insurances increases and who has the economy to buy a car . . . I haven’t

When people are stressed it [the over protectiveness] disappears because then they can move in to me and the wheelchair . . . and just step on . . . and . . . I have been out when they grab the handles [of the wheelchair] and just move me out of their way

Being questioned from different angles. When out in society the women had to explain their need for assistive devices to others they did not even know. They explained that people did not understand their lack of strength and they stated how they were met with an attitude characterized by distrust. When meeting other people, the women described how they felt attacked and they were falsely accused by others as being responsible for their walking problems. Women with MS said that they felt more vulnerable now when they were ill than the time when they were healthy, and they did not find enough strength to rebuff others thoughtlessness. When receiving help with basic needs in daily life the women expressed feeling violated due to being uncovered and exposed to unknown people who were there to assist them in their homes. The contact with the municipality made the women feel insulted due to having to answer personal questions that were irrelevant to their daily needs.

We are not as civilized as we would like to insinuate because just as if an animal within a flock is wounded he behaves differently . . . and yes of course depending
on the injury the flock might be helpful . . . somewhat helpful . . . but if it is
another type of injury they can attack . . . so depending of the flock and the injured
animal . . . you leave it . . . or you attack it . . . but we people are a bit like that too

I can’t understand it . . . it’s as unworthy as it ever can be . . . and I have started
not to answer those questions [questions concerning visiting the bathroom] earlier
I did . . . but I won’t do it today I refuse . . . I rather let it be

*Being doubted and disbelieved.* Despite being totally convinced that there was
something wrong with their bodies, women with MS felt that no one cared about their
stories and experiences. The felt fobbed off when they needed explanations, a feeling that
followed them and despite the fact that many years had passed, they still could feel that
their problems were imaginary. A feeling of frustration and not being important when
having to wait for appointments was expressed and the women said that when meeting
healthcare personnel no matter what, the problems was always related to their diagnosis.
Women with MS narrated that the homecare personnel did not listen to them and they
constantly had to explain how they wanted something to be done. Due to having being
forced to live with MS for a long time, advice often felt unnecessary and women asked for
a relation were they could be listened to.

The whole time I said that this is probably nothing [the dizziness] and everything
like that but she [healthcare personnel] said that it is something to take seriously . . .
from were do you get that . . . she said . . . you shouldn’t say like that . . . and
then I told her . . . I’m used to . . . for ten years I have been running here and I’m
just imagining the whole time . . . so it’s probably even now just imaginary . . .
I’m probably not that dizzy

They say it [advice] so nicely . . . have you thought of this . . . and yes . . . but
because of the fact that many go on telling me . . . and I just think . . . I have been
living with this [illness] for such a long time so I know

_Missing the right kind of help._ Women with MS said that it was hard trying to explain personal needs due to the unpredictability of the illness. There was a feeling of not being able to express oneself to others and the women said that no one had asked about their needs in daily life. Women with MS said that it would be easier for the healthcare personnel if they had more knowledge about the form of their daily life and what practical problems they were faced with on daily basis. They narrated how they felt like a burden for the homecare personnel who were stressed by the women’s basic needs. Trying to explain that their home was a home and not a work place was described, and the women said that their needs in daily life were wrongly estimated and that the municipality lacked knowledge about their illness and individual needs.

You feel quite lonely right there and then [at night time] . . . then you wish that you’ve had someone within . . . well in my apartment . . . it would help . . . that you need . . . well to lift a foot up on the pillow . . . but I was cramped so the pillow flew away

It is so horrible . . . it’s so horrible . . . and then I’m going to take a shower . . . and hang naked and show myself to everyone . . . they are able to send anyone here
and I shall get undressed and show myself to everyone . . . and I have told them that they should try to imagine what it’s like to hang there in a lift naked

**Comprehensive Understanding and Reflections**

In this study, we suggest that meanings of treatment from other people as experienced by women with MS can be understood as containing two concurrent dimensions where treatment from others can mean recognizing oneself through confirmation as well as being ignored due to missing togetherness with others (i.e., the two themes experiencing oneself as a valuable person and experiencing oneself as diminished). When reflecting on the findings, it was clear that the women with MS experienced confirmation by being understood by others, and as a contrast the women found themselves disconfirmed when questioned and met with a lack of understanding. In order to interpret the understanding of meanings of treatment for women with MS we find the thoughts of Gabriel Marcel and Martin Buber, concerning human relations, to be useful. We also relate empirical studies with a focus on living with illness and the experiences of treatment from others, to the understanding.

Central in the writings of Gabriel Marcel on the meaning of human existence is the idea of receptivity. Receptivity refers to the relationship between people founded on commitment. To receive another person means letting the other participate and letting the other feel welcomed [20]. In this study, women with MS expressed feelings of recognition and being welcomed by others to take part as a person who is no different from others. By meeting someone who gave their time to listen and by having space to express oneself implied experiences of strength and relief. According to Marcel [20,21] feeling recognised by others formulates human dignity by being met as a vulnerable person in a relationship amongst fellow beings. When being among others who were ill, the women with MS said that they felt a certain understanding. They never felt pitied by others who
shared similar experiences and they were being met by others who knew what it felt like to live with MS on daily basis. Toombs [4] argued that people who have the experience of being ill, share an empathic understanding of the manner in which the illness manifests itself in everyday life. According to Marcel [20] the discovery of having shared experiences brings people together in a mutual sense of belonging and shared communal understanding.

The women with MS described growing as a person due to feeling needed by others. According to Marcel [22] the experience of having someone who expects something of me can be understood as strengthening. When being met by healthcare personnel as a fellow human being, the women with MS expressed that they sensed that it was uncomplicated for healthcare personnel to assist and support the women’s needs in daily life. According to Buber [23] an understanding of the other person is only possible in an immediate relation between people formed by reciprocity. The relation of reciprocity occurs as glimpses where the other can feel relief and a person can grow from the relation to another based on mutual confirmation [24].

For women with MS in this study, in addition to the dimension of confirmation, there is also the dimension of being ignored were feelings of being questioned and met with a lack of understanding is salient in the women’s daily life. Marcel [25] argued that an unreal communication implies that a person understands what another is saying but he does not understand the person or the person’s experience. The unreal communication is possible due to the lack of communion and creates a feeling of not being able to be as oneself. The women with MS described being treated differently from when they were healthy and they believed that others did not understand them. They lacked understanding from others since the illness, with its exhaustion and pain was invisible, and in contrast they felt that others pitied them as an ill person due to the obvious difficulties with their
bodily condition. Söderberg, Lundman and Norberg’s research [2] pointed to a loss of credibility among women with fibromyalgia (FM), which threatened their integrity, due to being met with disbelief derived from the invisibility of the illness, and lack of other people’s understanding. In this study, the experience of women with MS, as being pitied as an ill person, has previously been shown to influence the experience of not being met in accordance with the own perceptions of the self [4,7].

Women with MS narrated an experience of not being welcomed and they felt that there was no room for them in the healthy society. This can be understood from Dahlberg’s research [28] which describes people’s feelings of being excluded, unwanted and feeling unnecessary, as an involuntary loneliness, which implies a lack of context, and a lack of participation in the world. Involuntary loneliness is out of the person’s control and implies feelings of not being good enough. Loneliness is described by Younger [26] as related to suffering due to the ill person’s sense of lacking connectedness with others. For the women with MS, there was a striking difference between being able to walk and sitting in a wheelchair and the women expressed being ignored and met in a ruthless way. Marcel [21] describes that ignoring and talking over another persons head implies feelings of being treated as an object and being relegated to the level of an object. Being ignored by others deprives a person’s status as a subject and imposes an experience of being excluded from a community to which the person feels they rightly belong.

When out in society the women with MS felt misunderstood by other people who questioned them and falsely accused them as being responsible for their walking problems. The feeling of being met with lack of understanding has been shown to threaten the dignity of people living with chronic illness [2,7]. A person’s dignity has two dimensions, meaning that the dignity of a person is constant as well as changeable. In its deepest sense dignity is something given, but in its changeable form a person’s dignity is
also influenced by culture and society [27]. According to Younger [26] visual as well as invisible signs of illness can imply a difference between how people experience themselves and how the ill person is perceived. For people who are ill, facing an unaccepting world produces feelings of shame due to being excluded.

The women suffering from MS described that no one cared about their experiences and they narrated having felt fobbed off when they sought explanations. The feeling of being fobbed of followed the women and this implied a feeling of having imaginary problems in daily life. Söderberg et al. [2] showed that for women with FM, the experience of not being a credible person implies a violation of the person’s dignity, due to not being taken seriously by others. Women with MS narrated that the homecare personnel did not listen to them and that they constantly had to explain their needs. This is in line with Jumisko et al. [15] who showed that people living with TBI and their close relatives long for the right kind of help, but it is not always easy to receive support in accordance with daily needs. In this study, women with MS described advice from homecare personnel as being unnecessary and they asked for relations were they could be listened to. Dahlberg [28] described how being offered a superficial and not a genuine companionship creates loneliness, despite actually being with others.

The women with MS said that no one had asked about their daily needs and they felt like a burden to homecare personnel who were stressed by the women’s daily necessities. When people who are ill turn to a carer, and reveal the suffering they experience, it is hard when their needs are not met. For people who are ill, loneliness has a greater power due to the vulnerability of suffering and needing care [28]. Due to the unpredictability of the illness, the women with MS described how it was hard trying to explain personal needs and felt that their daily needs were underestimated. According to Dahlberg [28] the experience of not being acknowledged as a person with needs that are
derived from the everyday life, contributes to the negative experience of loneliness and causes suffering due to feelings of abandonment.

**Methodological considerations**

The findings of this study can be transferred to similar situations. We chose a phenomenological hermeneutic interpretation because of its relevance for describing meanings of people’s experiences. The sample size of 15 women was sufficient in order to gain richness in data. The interpretation we present in this study is the one we found to be the most reasonable. According to Ricoeur [19] a text can always be interpreted in more than one way. In this study we paid attention to keeping our preunderstandings in check (cf. [29]) Through critical peer discussions concerning our evolving understanding of the phenomenon (cf. [19]).

**Conclusions**

In this study, meanings of treatment for women with MS are comprehended as containing two concurrently dimensions. In the first dimension, women with MS experiences confirmation by being understood by others, meanwhile in the second dimension women with MS find themselves ignored by being misunderstood and questioned. The need to support women’s experiences of being confirmed is in this study, obvious and authorities, the municipality, homecare and healthcare officials as well as personnel ought to consider these findings in their desire to support of strengthen the situation of women with MS in accordance with their daily needs.
References


[15] Jumisko E, Lexell J, Söderberg S. The experiences of treatment from other people as narrated by people with moderate or severe traumatic brain injury and their close relatives. Disability and Rehabilitation 2007; 1-9, i-First article.


**DISSERTATIONS FROM THE DEPARTMENT OF HEALTH SCIENCE, LULEÅ UNIVERSITY OF TECHNOLOGY, SWEDEN**

**Doctoral theses**

**Terttu Häggström.** Life-story perspective on caring within cultural contexts: experiences of severe illness and of caring. (Nursing) 2004.

**Inger Jacobson.** Injuries among female football players. (Physiotherapy) 2006.

**Karl Elling Ellingsen.** Lovregulert tvang og reflektiv praksis. (Health Science and Human Services) 2006.


**Inger Lindberg.** Postpartum care in transition: parents’ and midwives’ expectations and experience of postpartum care including the use of videoconferencing. (Nursing) 2007.

**Åsa Widman.** Det är så mycket som kan spela in – en studie av vägar till, genom och från sjukskrivning baserad på intervjuer med långtidsjukskrivna. (Health Science and Human Services) 2007.


**Gunilla Isaksson.** Det sociala nätverkets betydelse för delaktighet i dagliga aktiviteter: erfarenheter från kvinnor med ryggmärgsskada och deras män. (Health Science and Human Services) 2007.

**Nina Lindelöf.** Effects and experiences of high-intensity functional exercise programmes among older people with physical or cognitive impairment. (Physiotherapy) 2008.

**Åsa Engström.** A wish to be near: experiences of close relatives within intensive care from the perspective of close relatives, formerly critically ill people and critical care nurses. (Nursing) 2008.

**Catrine Kostenius.** Giving voice and space to children in health promotion. (Health Science and Human Services) 2008.

**Anita Melander Wikman.** Ageing well: mobile ICT as a tool for empowerment of elderly people in home health care and rehabilitation. (Physiotherapy) 2008.

**Sedigheh Iranmanesh.** Caring for dying and meeting death: the views of Iranian and Swedish nurses and student nurses. (Nursing) 2009.

**Birgitta Lindberg.** When the baby is premature. Experiences of parenthood and getting support via videoconferencing. (Nursing) 2009.
Licentiate theses

Marja Öhman. Living with serious chronic illness from the perspective of people with serious chronic illness, close relatives and district nurses. (Nursing) 2003.

Kerstin Nyström. Experiences of parenthood and parental support during the child's first year. (Nursing) 2004.

Eija Junisko. Being forced to live a different everyday life: the experiences of people with traumatic brain injury and those of their close relatives. (Nursing) 2005.


Carina Nilsson. Using information and communication technology to support people with serious chronic illness living at home. (Nursing) 2007.


Christina Harrefors. Elderly people’s perception about care and the use of assistive technology services (ATS). (Nursing) 2009.

Lisbeth Eriksson. Effects and patients’ experiences of interactive video-based physiotherapy at home after shoulder joint replacement (Physiotherapy) 2009.


For purchase information:
Department of Health Science, Luleå University of Technology, S-971 87 Luleå, Sweden.