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Meanings of Feeling Well for Women With Multiple Sclerosis

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Abstract

In research concerning multiple sclerosis (MS), the factors that 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 utilized 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 to confirm women's experiences of feeling well, despite living with the consequences of MS. Health care professionals will find the results of this study useful when they reflect on and formulate the care of women with MS when attempting to support the latter's desire to feel well in their daily lives.

Keywords

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 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) showed that people living with a traumatic brain injury (TBI) described that when the unfamiliar life with TBI became familiar, they experienced feeling well. Similar to this, Alsaker, Bongaardt, and Josephsson (2010) pointed out that women with chronic rheumatic conditions strove 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, 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 and 40 years. Next to accidents, it 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 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 (Devins et al., 1993; Sprangers et al., 2000). 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 have a negative impact

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on the quality of life. Uncertainty, discrimination, problems in accessing public places, and economic difficulties were factors that engendered a constant struggle. Despite these debilitating factors, women with MS still strove for well-being. Setting personal goals, maintaining valuable roles, trying out different ways of living to keep up with interests, and maintaining relationships and contact with other people were seen as positive forces in life, and these were also considered as ways in which to experience well-being (Dyck, 1995; Reynolds & Prior, 2003).

According to Brunet, Hopman, Singer, Edgar, and MacKenzie (1996), women with MS seem to cope with the illness better than men, a finding that contrasted with Miller and Dishon's research (2006), in which they found that women experience a lower life quality than men. Studies have shown that occupational conditions, changes in economic circumstances, depression, fatigue, and disabilities are factors that affect life quality among people with MS (Amato et al., 2001; McCabe & De Judicibus, 2005; Miller & Dishon, 2006). 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). Study findings have called attention to the problems of measuring well-being, and researchers have advocated research that focuses distinctly on expressing people's personal experiences (Brunet et al., 1996; Forbes, While, Mathes, & Griffiths, 2006; Miller & Dishon, 2006). Fawcett and Lucas (2006) noted the importance of health care based on individual needs, and Toombs (2004) stated 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 well-being has been undertaken with a mainly quantitative approach (i.e., with focus on quality of life). Findings point to problems in daily life, but 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 has not been touched on. Factors that 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 included being an adult woman with a secondary progressive type of MS whose 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 between 12 and 37 years (median: 32 years). The time elapsed since diagnosis varied from 7 to 34 years (median: 24 years). Eight women were married, 3 were cohabiting, and 4 were single. Ten women were receiving disability pension, 3 a state pension, and 2 were working part time. All of the women were in need of mobility aids or special assistive 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 provide further information, and to obtain informed consent, a letter was sent to the women. This letter included information about the study and a reply form on which informed consent to participate could be given. After they had agreed to further contact, the first author telephoned each woman to arrange for an interview.

Interviews

Individual audiotaped interviews were conducted using a narrative approach (cf. Mishler, 1986; Sandelowski, 1991). All of 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 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 for 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

Because 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. 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 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 differences in meaning. Based on similarities and differences, the formulated meaning units then were abstracted into subthemes and one major theme (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). We compared the major theme and subthemes with the naïve understanding 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 in as open-minded a manner as possible, with an awareness of our preunderstandings as nurses and as researchers in this area.

Findings

Naïve Understanding

The naive 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 was, 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 fact 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 seemed 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 below and illustrated with quotations from the interviews. 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 one on which they could get up in the 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. The women said that when their bodies functioned with some predictability, meaning that they were able to do things that 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 their own person and not totally dependent on the family—factors that 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 is good just to get outside. I think it feels good.

Feeling contented. The women with MS described that they no longer fretted 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 spoke of needing an inner strength to approach daily life. It was vital to encourage themselves, 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 described changing perspectives about life and seeing the essentials. There was a feeling of approaching daily life as it was, 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, okay, well its four o'clock, but I have been feeling well today, without a bad conscience.

> There are quite a lot of things that 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 the 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. They 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 their children 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 they could do something good for others and support others in need:

> He [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 they 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' comments 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 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 support organization. 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

As a result of this study, our suggestion is that meanings of feeling well for women with MS manifest themselves 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) stated 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, the results of this study show 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 are held back and health is unobtrusive. From this study it can be understood that finding a pace at which daily life goes on meant that women with MS felt well when illness was kept in check. By finding a balance in daily life, wherein illness was not the dominant experience, the women felt well. This can be understood from Gadamer (1996), who claimed 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 that cannot be measured.

Feeling well for women with MS was strongly related to how the body felt, and meant having the power to do the ordinary, such as being able to get up in the morning and start a good day. The women recounted that doing the ordinary was being able to just sit on the balcony, get properly dressed, and 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 toward the surrounding world. For women with MS, feeling well was understood as if the rhythm of the body in some sense was predictable during the course of the day.

The participants described getting used to the fact that a lot of things could no longer be taken for granted. There was a feeling of approaching daily life as it was, and learning how to live. According to Toombs (1995), reclaiming life is possible when one lives with an illness. Because 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) drew on Heidegger's philosophy when they showed the experience of "letting be," as taking on the circumstances of life and being reconciled to the possibilities available. From this, letting be 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 described 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 was, and focusing on the essentials in life. They felt well by choosing strength and encouraging themselves. According to Frankl (1993), the essential in life is the specific meaning that people ascribe to 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 solitude is pleasant and restful, a turning toward oneself in an experience of well-being (Dahlberg, 2007). Tillich (1973) understood being alone as a natural desire for solitude, something that 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 it gives them through the senses. People then use this knowledge 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 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) 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 learned 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 traumatic brain injury. Marcel (1963) argued that the experience of being welcomed by others formulates human dignity, and people's experiences of health are not to be seen as a condition that 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 that guide human understanding ought to be slackened. 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 article 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 findings of this study present 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 transferred to similar situations (cf. Ricoeur, 1976).

Conclusion

In conclusion, the findings of this study show that it is possible for women with MS to feel well despite living with illness. The findings can be used to confirm women's experiences of finding a pace at which 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 to support the latter's sense of feeling well in daily life. To strengthen the well-being of women with MS, it is important to focus on what it is that makes women with MS feel well despite being ill.

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