

EMPIRICAL STUDIES

Meanings of being received and met by others as experienced by women with MS

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Abstract

In order to elucidate meanings of being received and met by others as experienced by women with multiple sclerosis (MS) we conducted a qualitative inquiry. We interviewed 15 women with MS and analysed the interviews with a phenomenological hermeneutic interpretation. The findings were presented in two themes: experiencing oneself as a valuable person and experiencing oneself as diminished. Meanings of being received and met by others, as experienced by women with MS, can be understood as containing two dimensions where treatment from others can mean recognising oneself through confirmation, as well as being ignored due to missing togetherness with others.

Key words: *Interviews, lived experience, multiple sclerosis, nursing, being received and met, women*

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In this study we report the findings of a qualitative inquiry. We interviewed 15 women with multiple sclerosis (MS) about their experiences of being received and met. The interviews were analysed using a phenomenological hermeneutic interpretation.

Chronic illness has been shown to have a considerable impact upon people's daily lives. Living with chronic illness restricts people's daily lives and it causes loneliness and feelings of being excluded by others (Öhman, Söderberg, & Lundman, 2003; Sexton & Munro, 1988; Söderberg, Lundman, & Norberg, 1999). Illness is a most subjective experience and the meaning that people give their experience is embedded in the illness experience itself. Bodily dysfunction tends to disrupt a person's engagement in the world and illness affects the habitual way of being in the world (Toombs, 1992). Multiple sclerosis is an autoimmune inflammatory demyelinating illness of the central nervous system, with a course that varies and a prognosis that is uncertain. Next to accidents, it is known as the leading cause of disability among young adults (Vukusic & Confavreux, 2001). Studies (Olsson, Lexell, & Söderberg, 2005, 2008; Toombs, 1992;

Yorkston, Klasner, & Swanson, 2001) have shown the changes in daily life affecting people who live with MS and how meeting expectations from oneself 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 (Olsson et al., 2005, 2008). When exploring the stigma that people with multiple sclerosis experience in social relations, Grytten and Måseide (2006) claimed that people with MS felt ignored or, conversely, experienced that people overemphasised the illness during social interaction. People with MS describe the time before an established diagnosis as a time of suffering, where they have experienced 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 with the illness. After the establishment of a diagnosis, people with MS describe a constant

struggle to maintain a daily life that resembles the life they led when healthy (Courts, Buchanan, & Werstlein, 2004). Olsson, Skär, and Söderberg (2010) highlighted experiences of feeling well among women with MS and showed that such women feel well when they are being understood and when they feel needed; this also implied that the women could find a pace in which to continue their daily lives.

Studies (Courts et al., 2004; Koopman & Schweitzer, 1999; Miller, 1997; Toombs, 1992) 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 (2005) and Koch and Kelly (1999), 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 that 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 (Jumisko, Lexell, & Söderberg, 2007).

In short, there are, to the best of our knowledge, no studies that focus specifically on meanings of being received and met by others as experienced by women with MS. It is known that people living with the illness 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 elucidate meanings of being received and met by others as experienced by women with MS.

Method

Participants and procedure

Fifteen women diagnosed with secondary progressive MS participated in the study. The criteria for participation were that they were adult women, with a secondary progressive type of MS, and that their daily lives were influenced by MS. The women's ages ranged from 35 to 70 years (md: 54 years)

and they had experienced symptoms for about 12–37 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 a 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. 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 of the women preferred to be interviewed in their home. The women were asked to talk about experiences of being received and met by others. 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 demand for informed consent, confidentiality, consequences, and usage were estimated to have been achieved and the participants were guaranteed confidentiality and an anonymous presentation of findings.

The phenomenological hermeneutic interpretation

As our aim was to elucidate meanings of being received and met as experienced by women with MS, a phenomenological hermeneutic interpretation was chosen to analyse the transcribed interviews (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). Using this method, attempts are made to explain and, from there, understand the meaning of a phenomenon by the interpretation of narratives. To gain an 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 began 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 were then abstracted into seven subthemes and two themes (cf. Lindseth & Norberg, 2004; Ricoeur, 1976). 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. Lindseth & Norberg, 2004; Ricoeur, 1976). The chosen literature of interpretation was aimed at revising, widening, and deepening our understanding of the text. When the literature was chosen, we did not force the literature's perspective onto the interview text, but rather let the chosen literature illuminate the interview text, and the interview text illuminate the chosen literature (cf. Lindseth & Norberg, 2004). 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

Naïve understanding

Meanings of being received and met by 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 there was a perception of being governed by society. As a contrast to being met in an exclud-

ing manner, there were alternative feelings of being understood and taken seriously by others. Being received and met in a manner that was no different from how they were treated when healthy was deemed important, and when sharing experiences with others who lived with MS, the women's feelings of being received and met 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 in being understood in accordance with their own outlook regarding their daily needs.

Structural analysis

The structural analysis resulted in two themes and seven subthemes. The themes and subthemes are presented in the 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 received and met by others in the same way as they had been 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 both 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 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 help. In situa-

tions where healthcare personnel approached the women and recognised them, they felt visible and welcomed as individuals. The women stated that they did not have to offer 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 these women explained how they were being taken seriously by healthcare personnel who understood the gravity of the situation. In addition, they also 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, that you can tell if they have close relatives who has 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 received and met differently than from the time when they were healthy. Sometimes they experienced that they were received in a similar way to 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. These women claimed that the feeling of being pitied 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 a 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 they had with authorities as being 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 characterised 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 the thoughtlessness of others. 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 civilised 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 on 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'd 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. They 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 of not being important when having to wait for appointments was expressed, and the women said that when meeting healthcare personnel, the problems were 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, the advice often felt unnecessary and women asked for a relationship where 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 where 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 offer 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. The women claimed that it would be easier for the healthcare personnel if they had more knowledge about the form of their daily lives, 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 clearly stressed by the women's basic needs. They described trying to explain that their home was a home and not a work place, and the women said that their needs in daily life were wrongly estimated; indeed, they argued 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 fell 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

In this study, we suggest that meanings of being received and met by others as experienced by women with MS can be understood as containing two concurrent dimensions: treatment from others can mean recognising 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 ignored

when questioned and met with a lack of understanding. In order to interpret the understanding of meanings of being received and met as experienced by 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 being received and met by others, to the understanding.

Central to the writings of Gabriel Marcel regarding 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 both participate and feel welcomed (Marcel, 2002). In this study, women with MS expressed feelings of recognition and being welcomed by others, which helped them to act as a person who is no different from others. Meeting someone who listened and having space to express oneself implied experiencing strength and relief. According to Marcel (1963, 2002) feeling recognised by others formulates human dignity, as it implies 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 (1992) 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 (2002), 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 individuals due to feeling needed by others. According to Marcel (1978), the experience of having someone who expects something of me can be experienced as strengthening. When met by healthcare personnel as a fellow human being, the women with MS sensed that it was uncomplicated for healthcare personnel to assist and support the women's needs in daily life. According to Buber (1994), an understanding of the other person is only possible in an immediate relation between people formed by reciprocity. A reciprocal relationship occurs when the other can feel relief and a person can grow from the relation to another based on mutual confirmation (Buber, 1997).

For women with MS in this study, in addition to the dimension of confirmation, there is also the dimension of being ignored when being questioned and met with a lack of understanding is salient in the women's daily lives. Marcel (1950) 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 a 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 et al.'s research (1999) 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 the 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 (Olsson et al., 2008; Toombs, 1992).

Women with MS narrated an experience of not being welcomed and they felt that there was no room for them in a society that emphasises health. This can be understood from Dahlberg's research (2007) that 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 beyond the control of the individual and involves feelings of insufficiency. Loneliness is described by Younger (1995) as being 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 feelings of being ignored and being met in an insensitive manner. Marcel (1963) has described how being ignored involves feelings of 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 in society, the women with MS felt misunderstood by other people who questioned them and falsely accused them of being responsible for their difficulties in walking. The feeling of being met with lack of understanding has been shown to threaten the dignity of people living with chronic illness (Olsson et al., 2008; Söderberg et al., 1999). A person's dignity has two dimensions, which suggests 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 (Edlund, 2002). According to Younger (1995), visible 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 a sense of exclusion.

The women suffering from MS described how no one cared about their experiences and they narrated having felt fobbed off when they sought explanations. The feeling of being fobbed off followed the women and this implied feelings of having imaginary problems in daily life. Söderberg et al. (1999) have shown 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 the findings of Jumisko et al. (2007) who showed that people living with TBI, together with their close relatives, long for the right kind of help, but it is not always easy to receive support in accordance with their daily needs. In this study, women with MS described the advice they received from homecare personnel as being unnecessary and they asked for a relationship where they could be listened to. Dahlberg (2007) 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 influence due to the vulnerability of suffering and needing care (Dahlberg, 2007). Due to the unpredictability of the illness, the women with MS described how it was difficult to explain personal needs and they felt that their daily needs were underestimated. According to Dahlberg (2007), the experience of not being acknowledged as a person with needs that are derived from 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. It is when the reader can integrate

the interpretation into her or his world that it can become productive in human life and used to improve care (cf. Lindseth & Norberg, 2004). We chose a phenomenological hermeneutic interpretation because of its relevance for elucidating meanings of people's experiences. During the interviews, the women narrated their lived experiences freely and they expressed that they understood the meaning of questions being asked. The interviews were rich, had depth, and gave variations of lived experiences of the chosen topic (cf. Lindseth & Norberg, 2004). The interpretation we present in this study is the one we found to be the most reasonable. According to Ricoeur (1976), a text can always be interpreted in more than one way. The most probable interpretation is not contradicted by data. A probable interpretation has internal consistency and widens and deepens the understanding. We considered and compared possible interpretations (cf. Lindseth & Norberg, 2004) in critical discussions with peers (Ricoeur, 1976). This study sets down one way to understand meanings of women's experiences of being received and met when living with MS. In this study, we paid attention to keeping our pre-understandings in check (cf. Dahlberg, Dahlberg, & Nyström, 2008) through critical peer discussions concerning our evolving understanding of the phenomenon (cf. Ricoeur, 1976). During interviews, the pre-understanding was checked by the use of probing questions when needed.

Conclusions

In this study, meanings of being received and met by others as experienced by women with MS are comprehended as containing two concurrent dimensions. In the first dimension, women with MS experience confirmation by being understood by others; while in the second dimension, women with MS find themselves ignored by being misunderstood and questioned. In this study, the need to support women's experiences of being confirmed is obvious and authorities, the municipality, homecare and healthcare officials, as well as personnel ought to consider these findings in their desire to support and strengthen the situation of women with MS in accordance with their daily needs.

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