

Unmet needs of caregivers of severely affected multiple sclerosis patients: A qualitative study

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ABSTRACT

Objective: Multiple sclerosis (MS) patients' caregivers are sometimes considered as "hidden patients." How much more this might be true for caregivers of *severely* affected MS patients has so far been scarcely studied. Palliative care also addressing relatives' needs might therefore be very relevant for these caregivers. However, we do not yet know which unmet needs they have and how these could be met. Our aim was to gain an insight into the subjectively unmet needs of caregivers of severely affected MS patients in Germany.

Method: The study employed a qualitative cross-sectional approach for assessing unmet needs. Twelve caregivers of severely affected MS patients were recruited using a convenience sampling approach. Face-to-face interviews were conducted, audiotaped, and transcribed verbatim, followed by qualitative content analysis.

Results: Unmet needs were sorted into the following categories: "relationship to physician," "individual support by the healthcare system," "relationship to the individual severely affected by MS," "end-of-life issues," "self-care," and "higher awareness of MS." Caregivers tended to group the unmet needs of their care recipients with their own and rarely focused on their own wishes and restrictions.

Significance of Results: A close patient–caregiver dyad makes it difficult to differentiate unmet caregiver needs. However, the palliative care approach might help caregivers of severely affected MS patients by answering questions on disease progress and end-of-life issues, as well as by offering respite care, support for self-care, and help in preserving one's identity, and also anticipating the time to come after the death.

KEYWORDS: Caregivers, Severe multiple sclerosis, Palliative care, Qualitative study

INTRODUCTION

Relatives and friends are of special importance for severely affected multiple sclerosis (MS) patients (Golla et al., 2012; Strupp et al., 2012; Galushko et al., 2014), frequently enabling home care (Dunn, 2010) and supporting not only patients but also the

community and the healthcare system. MS caregivers bear a high level of physical and emotional burden (McKeown et al., 2003; Wollin et al., 2006), and their quality of life is rather low (Aronson, 1997; Patti et al., 2007; Rivera-Navarro et al., 2009; Buchanan & Huang, 2011). They are in need of psychological, social, healthcare, and financial support (Dunn, 2010; Kouzoupis et al., 2010; Akkuş, 2011; Gupta et al., 2012), require increasing access to and training in MS-focused care (Dunn, 2010; Buchanan et al., 2011), and need to protect and retain their own identities (Dunn, 2010; Hughes et al., 2013). MS patients

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and their caregivers often seem inseparable, as a caregiver's well-being depends on the patient's well-being and vice versa (Knight et al., 1997; Chipchase & Lincoln, 2001; Gupta et al., 2012), a state that is especially pronounced if the caregivers are spouses (Knight et al., 1997; Boeije et al., 2003; Buchanan et al., 2011). A caregiver's strain increases if their related MS care recipients suffer from hopelessness, social isolation, problems with the activities of daily living, sudden mood changes, motor problems, incontinence, and pain, and if they cannot prevent admission to a nursing home (Knight et al., 1997; Chipchase & Lincoln, 2001; Boeije et al., 2003).

The unmet needs of caregivers caring for severely affected MS patients are rarely studied, or they are not considered as a separate group (Wollin et al., 2006). However, these MS caregivers are those who would predominately contact palliative care (PC) services, if PC were to further open up for MS and be integrated in a standardized manner (Higginson et al., 2008; 2009; Edmonds et al., 2010; Strupp et al., 2014b). To focus not only on patients' (Higginson et al., 2006; Edmonds et al., 2007a; 2007b; Golla et al., 2012; Strupp et al., 2012; Galushko et al., 2014) but also on relatives' unmet needs is one main aspect stated in the WHO definition of palliative care (WHO, 2002). Thus, in our larger research project of assessing the unmet needs of severely affected MS patients in Germany (Golla et al., 2012; Buecken et al., 2012; Galushko et al., 2014; Golla et al., 2014; Strupp et al., 2014a), we also focused on the unmet needs of caregivers of the severely affected MS patients.

METHODS

Recruitment

We recruited primarily caring relatives who deemed their care recipients as severely affected by MS using a convenience sampling approach, as the original plan of purposive sampling could not be complied with due to recruitment difficulties. Subjective assessment of one's suffering was the decisive factor for recruitment (Golla et al., 2012; Strupp et al., 2012; Buecken et al., 2012; Galushko et al., 2014; Golla et al., 2014; Strupp et al., 2014a), as in PC, where this should be the most decisive factor triggering an intervention. Further patient data were not gained within this study. MS relatives were informed about the study by leaflet and by personal inquiry in regional MS self-help groups, in a nursing home specialized for young people with disabilities, and in the neurological department at the University Hospital of Cologne. Moreover, one MS outpatient treated at the University Hospital offered to act as intermedia-

tor between the study center and potential participants by establishing telephone contacts. Interested relatives were called (by MG and SM) for open questions and to set an interview date in case of consent. Caring relative-like friends could also be included in the study. In the following, we will speak of caregivers in the sense of both caring relatives and caring relative-like friends.

Data Collection

Semistructured face-to-face interviews (Flick, 2000) were conducted by skilled qualitative interviewers who had experience in palliative care (MG, SM), at a place preferred by the interviewees. Interviewers had no prior contact with patients. An interview guideline was utilized (see Table 1). Fieldnotes were taken. Interviews were audiotaped, transcribed verbatim, and were not returned to participants for comment or correction. Participants filled in a short questionnaire collecting sociodemographic data and gave written informed consent. Transcripts and questionnaires were pseudonymized. Approval from the medical research ethics committee of the University Hospital of Cologne was obtained (IRB #06-191).

Analysis

The interviews were analyzed by qualitative content analysis (Mayring, 2004). First, the interviews were analyzed using global analysis (Legewie, 1994). Parts of interviews indicating caregivers' unmet needs were identified and then further analyzed: Interviews were coded (by MG, SM, HG) using constant comparison to reveal minimal and maximal contrasts. Emerging codes were constantly compared, and similar content

Table 1. *The interview guideline encompasses questions related to the following fields:*

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- Caregivers' present living situation
 - Caregivers' change of life due to care recipients' disease
 - Caregivers' everyday challenges, problems, and burden
 - Caregivers' coping strategies and resources
 - Caregivers' wishes, unmet needs, and expectations in general and concerning their family and the physicians, hospital staff, social workers involved in caring for their ill relatives
 - Definition of "being severely affected by MS"—what it means to caregivers
 - Associations with attitude toward palliative care
 - Personal additions
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Table 2. Characteristics of the interviewed caregivers

Characteristics Interview	Sex	Age	Family Situation	Occupation State	Relation to Patient	Patient Living in Nursing Home	Place of Interview	Patient Present During Interview
1	Male	45	Widowed	Full-time working	Partner	No	At hospital	Yes
2	Female	40	Married, 1 child	Unemployed at this time	Sister	No	At home	No
3a	Female	70	Married, 1 child	Pensioners	Parents	No	At home	No
3b	Male (married couple)	76						
4	Female	78	Widowed, 3 children	Pensioner	Mother	Yes	At home	No
5	Male	66	Married, 1 child	Pensioner	Spouse	No	At home	Yes
6	Female	59	Married, 1 child	Pensioner	Caring friend	Yes	At hospital	No
7	Male	50	Married, 2 children	Full-time work	Spouse	No	At home	Yes
8	Male	70	Widowed, 2 children	Pensioner	Father	Yes	At home	No
9	Female	70	Widowed, 1 child	Pensioner	Mother	Yes	At nursing home	Yes
10	Female	59	Widowed, 1 child	Pensioner	Mother	Yes	At home	No
11	Female	30	Married	Full-time work	Daughter	No	At home	No

from different interviews were combined into preliminary categories. Categories at a higher level of abstraction were needed in order to be applicable to the whole dataset. Both categories and subcategories were iteratively refined and key categories evolved (Corbin & Strauss, 2008). The data and related codes were discussed in a multi-professional fashion among the authors (MG, SM, HG, RV) (Pope et al., 2006). Our study conforms to the consolidated criteria for reporting qualitative research (COREQ) guidelines for reporting qualitative research (Tong et al., 2007).

RESULTS

Participants

Twenty caregivers showed interest in our study. Contacts were established as follows: at the University Hospital (8), in specialized nursing homes (8), and via an MS patient intermediary (4). No feedback came from the MS self-help groups. Ultimately, 12 of these caregivers agreed to participate (for sociodemographic data, see Table 2). Reasons for refusal cited were: nonattendance of a special family member at the interview or lacking German language abilities. Four caregivers insisted on their care recipient being present during the interview, and one married couple caring together for their diseased adult child agreed to a joint interview only. Due to difficulties in recruitment, we decided to go through with these interviews, though anticipating possible bias. Interviews were conducted at home (8, one with two participants), at the University Hospital (2), and at a nursing home (1), and took 30 to 90 minutes. During interviews, caregivers repeatedly had to be reminded that their unmet needs were of interest, not those of their care recipients. Cited reasons for which caregivers regarded their relatives as severely affected by MS were: fundamental, unpredictable changes in life forced by the MS (Int. 2); disastrous, unmanageable living situations (Int. 6, Int. 7) leading to helplessness (Int. 9); increasing physical barriers (Int. 8); and being continuously dependent on outside help (Int. 10).

Categories

The unmet needs of caregivers of severely affected individuals with MS can be grouped into the following framework of six categories (Table 3).

Relationship to Physician

Only one caregiver was satisfied with physicians' medical care for the patient and the physician–patient or physician–relative relationship (Int. 5). More often, caregivers complained about both of these issues

Table 3. *Categories of unmet needs of caregivers of severely affected individuals with multiple sclerosis*

Categories
1 Relationship to physician
2 Individual support by the healthcare system
3 Relationship to individual severely affected by multiple sclerosis
4 End-of-life issues
5 Self-care
6 Higher awareness of multiple sclerosis

(Int. 4, Int. 7, Int. 10, Int. 11) and described physicians as being “incompetent,” “unfriendly,” “insensitive,” and “indelicate.” One caregiver suggested communication training for medical students to prevent such behavior in the future (Int. 2):

For example, in hospitals, maybe someone could ask, if relatives have the necessity to talk, and you don’t want to have the feeling of being pushed aside. (...) I know, doctors are very busy, and I don’t want to interfere. (Int. 2, ll. 319–324).

Caregivers wished that physicians recognized the burden and needs of both the care recipients and their caregivers (Int. 1, Int. 4, Int. 6) but felt that most physicians only focused on the patients’ situation (Int. 6). Some of the interviewees did not feel as if they were being taken seriously by their physicians. Although the interviewees felt they were experienced in handling MS, they claimed that physicians did not appreciate this and excluded them from the decision-making process:

Then the doctor sent us out of the room. Now he has only to deal with the patient, not with us. (Int. 3, ll. 479–481)

I felt like a disturbing factor. (Int. 2, l. 251)

The interviewed couple wanted to be more involved in the medical care plan of their care recipient (Int. 3). Another participant wished for consultation meetings about the patient’s precise situation, without the patient being present (Int. 2).

Individual Support by the Healthcare System

Interviewees criticized the lack of profound knowledge in physicians treating MS patients (Int. 1, Int. 4, Int. 11). An unambiguous, early diagnosis of MS would build their confidence in the physicians (Int. 4, Int. 10, Int. 11). Recognizing and naming early symptoms like double vision, ataxia, or incontinence

as signs of MS would help in dealing with the disease (Int. 4). Opinions differed regarding nursing care services. Some caregivers considered them helpful, especially if they had a full-time occupation (Int. 5, Int. 7, Int. 10). Others regarded their support as insufficient and wished for a more specialized, individual, and time-intensive care lying beyond the possibilities of nursing services (Int. 3). One caregiver wished for workshops dealing with basic caring skills and would have appreciated an external person to mediate disputes between caregiver and care recipient, one who could bring up serious issues like the patient’s will to live:

His health is deteriorating, especially in the last six month, so that now I have really a lot of questions (...), and it is really difficult to talk about such things [like a living will]. I miss someone I can ask. (Int. 2, ll. 239–245; ll. 265–266)

Other caregivers needed more aids (e.g., an electric wheelchair) for their care recipient or a stairlift to improve their physical situation (Int. 5, Int. 7). They would also feel supported by transportation services for both the affected person and their caregiver (Int. 4, Int. 5).

Relationship to the Individual Severely Affected by MS

Caregivers had increasing difficulties in understanding their diseased relatives due to the behavioral and personality changes that had occurred during the progression of their disease. They noticed that this leads to discomfort on both sides (Int. 2, Int. 10). For example, social behavior within a family changed and was experienced as inappropriately strict or uncompromising:

We played Yahtzee, and he [the affected person] said, we haven’t even started, but she [the child] had already a good match. But he reacted very strictly. This was in my opinion really inappropriate, because she is only five. (Int. 2, ll. 61–66)

Caregivers were strained if their care recipients demanded an intuitive understanding of their needs. Although being aware of care recipients’ restrictions, caregivers wished that their dedicated care would be more appreciated (Int. 3, Int. 2). Being taken seriously by their care recipients meant to caregivers that they both had decided on things, like organizing care to avoid mismanagement and unnecessary work (Int. 2). Moreover, this could mean honestly and constructively discussing difficult topics like end-of-life issues or future plans (Int. 2):

Well, when I really make things clear and say, “We have to make out how we want to deal with each other,” then it is going to work. (Int. 6, ll. 175–176)

Some caregivers suffered from feelings of insufficiency and depression with severe self-blame despite constant commitment to the progressively diseased patient (Int. 3, Int. 4, Int. 10). They felt ashamed if they took a break (e.g., by traveling alone) and could not really enjoy being on their own while continuously thinking of the care recipient left at home (Int. 10). Their lifestyle was adapted to the patient’s demands the more the disease progressed. Often, family roles were redefined. Two male participants described how they now had to fulfill “women’s tasks” around the house (Int. 5, Int. 7).

End-of-Life Issues

Caregivers appreciated reliable information on symptoms and the changes that accompany disease progression, as they wanted to be well prepared. Information on the final stages of the disease was especially crucial for them but seldom communicated:

Recently someone told me that it is getting worse. I have to deal with more aggression. This was not a formal piece of information. They are all sugarcoated. This was from elsewhere. (Int. 2, ll. 266–273)

Important end-of-life issues included not only worries about death and dying of the care recipient but also of the caregiver’s own death. One mother feared for the welfare of her diseased daughter if she were to predecease her (Int. 9):

Sometimes I wish M. dies before I have to die. This is not a nice wish, but then I know she is well cared for. (Int. 9, ll. 453–456)

In contrast to this, another participant insisted that he would never give up hope in spite of the severe MS of his wife, and he refused to tolerate statements like “there is no help anymore” (Int. 7). None of the interviewees could imagine PC as a supporting approach for them. However, only very few had any knowledge of PC (Int. 1, Int. 2, Int. 4, Int. 7), and if they did, they regarded it as an approach to alleviating dying for cancer patients.

Self-Care

Self-care only played a minor role for the interviewees. If stated at all, they named their own resources as follows: work, leisure activities, and a belief in God with support from the faith community (Int. 3, Int. 5, Int. 9, Int. 10). One caregiver’s strategy for cop-

ing was to form unquestionable beliefs or mantras like “together we are strong” when feeling exhausted (Int. 7). Another felt protected by social withdrawal, as he wanted to escape the pity of others. He refused any kind of help until it was offered by family members (Int. 1). Only one caring mother was psychologically supported and felt relieved that she had learned to accept unchangeable things like the progression of her son’s disease (Int. 10).

Higher Awareness of MS

Caregivers felt that the community did not want to be confronted with disease and was afraid and helpless when dealing with disabled people (Int. 9, Int. 11). Caregivers therefore wished that MS, its disease course, and the associated complications were made more public to increase awareness, thus leading to less social isolation (Int. 1). In their view, social awareness of MS should start with a more disabled-friendly environment and appropriate technical devices like lowered curbs, transport connections with level access, or more disabled-friendly toilets (Int. 5, Int. 10, Int. 11). This would help to ensure the best possible autonomy for both care recipients and caregivers.

DISCUSSION

This study focused on the unmet needs of caregivers of severely affected MS patients, a group of MS caregivers who so far have been scarcely considered. This group is, however, of great interest to palliative care if its services are to open its doors to MS patients.

Recruitment and Caregivers

The inclusion criterion was that caregivers felt that their care recipient was severely affected (Golla et al., 2012; Buecken et al., 2012; Galushko et al., 2014; Golla et al., 2014). This could have involuntarily served as a barrier for caregivers to participate. Naming care recipients as *severely* affected could imply that the caregivers felt burdened by them and therefore might have developed feelings of guilt. It may have helped that patients were present during interviews, as was the case in four interviews. The unmet needs of the studied caregivers were strongly connected to those of their care recipients. Five of the six categories evolved were primarily associated with the care recipients or the relationship with them. Only the category “self-care” represented purely caregiver interests. These points stress the close dyad between MS patients and their caregivers (Knight et al., 1997; Chipchase & Lincoln, 2001; Boeije et al., 2003; Akkus, 2011) and that it may become stronger the more the disease progresses.

Unmet Needs of Caregivers

Relationship to Physician

Like patients (Buecken et al., 2012; Galushko et al., 2014) and health professionals (Golla et al., 2012), the caregivers in this study regarded a well-established patient–physician relationship as an important factor in coping with the disease. Caregivers also wished for an empathic relationship with patients' physicians, including receiving highly useful information on disease status, a crucial factor also known for caregivers of cancer patients (Soothill et al., 2003). In terms of their vital role, these caregivers criticized physicians for excluding them from important discussions and decisions concerning the affected persons. However, the caregivers' belief that they had the right to be involved in the treatment plan (Patti et al., 2007; Kouzoupis et al., 2010) and in decision-making processes may lead to difficult ethical issues (Toon & Southgate, 1987).

Individual Support by the Healthcare System

The caregivers in our study felt relieved if the unmet needs of the affected persons were met through individually adapted support and when they were themselves highly engaged. This again stresses their close relationship with the patient. External support was only appreciated if it served to mediate between caregivers and care recipients, and when offered to those who still maintained spheres of life other than caring (e.g., working life).

End-of-Life Issues

Due to an uncertain disease trajectory and a less distinct terminal care phase (McIlfratrick, 2007; Wilson et al., 2011), physicians seldom discuss end-of-life issues with MS patients, though it might be beneficial for patients and their families (Seeber et al., 2012). About a third of severely affected MS patients studied would like their doctors to address end-of-life issues with them and their caregivers (Buecken et al., 2012). MS caregivers want to understand MS and what will happen during the progression of the disease (Finlayson et al., 2008). The results of our study show that this is also true for end-of-life issues. This is reasonable, as end-of-life issues also raise many questions for caregivers. They have to prepare for the expected suffering of their care recipients, to develop their own coping strategies, or they might have to anticipate a situation where they might die before their care recipient.

An essential question neglected by the caregivers in this study is how they might realign their lives after the death of patients. Perhaps being separated from each other is simply unthinkable for them or

to anticipate a time after the care recipient's death might be taboo, as this may not only mean grief but also relief (Wollin et al., 2006). The latter might be hard on the conscience and is thus especially avoided in the presence of care recipients. Both severely affected MS patients and their caregivers might profit from the PC approach (Higginson et al., 2008; 2009; Edmonds et al., 2010; Strupp et al., 2014a; 2014b). Recognizing the special unmet needs of these caregivers after a patient's death might be a field of special importance for PC integration. Respite care, as known from children hospices (Champagne & Mongeau, 2012), could be one approach. However, in the current situation, health professionals and patients severely affected by MS often regard PC as a counter-intuitive approach for MS (Kümpfel et al., 2007; Voltz, 2010; Golla et al., 2014), a view supported by the caregivers in our study.

Relationship to the Individual Severely Affected by MS

During interviews caregivers mostly spoke of unmet needs concerning care recipients instead of their own needs or they grouped these with their own. This can be seen as a sign of a close relationship or even of a lack of differentiation, which might serve as a coping strategy. A dyadic adjustment has proved to have a positive effect on the relationship between caregivers and dependents (Pakenham, 2005), and a good relationship between caregivers and affected persons reduces the burden of caring (Chipchase & Lincoln, 2001). However, not all caring partners manage to align their lives with the affected individuals, and this is less likely with a longer illness trajectory (Pfleger et al., 2010). Caregivers who still care for their relatives when MS gets severe mostly live in a patient–caregiver dyad, as seemed to be the case for most of the caregivers in our study.

Self-Care

The caregivers in this study mainly neglected their own wishes and left themselves little space for self-care. To them, self-care meant support in reducing the caring burden, that is, it was primarily linked with MS and care recipients and only very little space was given solely for the caregivers' resources. The only ones mentioned were: work, some leisure activities, faith in God, and psychological support. Paying less attention to themselves (Gulick, 1998), while simultaneously suffering from increased physical (Buhse, 2008) and psychological burden (Janssens et al., 2003) and from impaired social life (Bogosian et al., 2009) is often the case for MS caregivers (Kouzoupis et al., 2010). The results of our study indicate that this seems to be even more pronounced for

caregivers of individuals with severe MS. Enabling respite and self-care and assistance in maintaining an identity apart from the caregiver role could be a starting point for integration of palliative care.

Higher Awareness of MS

Caring for individuals with severe MS definitely supports not only the care recipient but also the community (Dunn, 2010; O'Hara et al., 2004). The expressed unmet need of study participants for a greater awareness of MS indicates that, apart from severely affected MS patients (Strupp et al., 2012), their caregivers also feel socially isolated due to the MS. The community should undertake more effort to socially support these caregivers and make them feel an important and accepted part of the community, which would improve caregiver well-being (Sherman et al., 2007).

LIMITATIONS OF THE STUDY

Since we wanted to concentrate on caregivers' perceived burden and feelings, this study focused on primarily caregivers of MS patients deemed by their caregivers to be severely affected by the disease. Therefore, MS patients' self-report on feeling affected and their objective clinical status were not assessed, which limits our data. Caregivers alone presented the study focus and not caregivers *and* care recipients as a group. This approach led to difficult recruitment, as caregivers perhaps felt inhibited to name their care recipients as severely affected. A mere convenience strategy was finally employed for recruitment, as the original plan of purposive sampling could not be complied with. Therefore, interviews could not be conducted up to theoretical saturation. In some cases, it helped that patients were allowed to be present during interviews if this was set as a condition to participate. In these cases, the results might be biased, as an individual interview might have facilitated the expression of caregivers' feelings, concerns, and unmet personal needs. Due to these constrictions, our study results cannot be generalized, but they can serve to help us gain an insight into the view of caregivers of severely affected MS patients. The recruitment difficulties, on the one hand, limit our findings, but, on the other, they emphasize how closely related these caregivers are with their care recipients, underlying how difficult it is to reach these caregivers and encourage them to advocate for their own unmet needs.

CONCLUSION

Caregivers and patients severely affected by MS form an established dyad, which makes it difficult to inves-

tigate caregivers separately. Yet, to study this caregiver group is necessary since their quality of life influences the quality of life of the patients and vice versa. The palliative care approach might be useful not only for patients with severe MS but also for their caregivers. The uncertainties involved with progressive disease and end-of-life issues are important for them, as well as the possibility of respite and self-care to maintain their own identity, one outside the role of caregiver, which in some way anticipates the time after the death of their beloved care recipient.

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CONFLICTS OF INTEREST

The authors state that they have no conflicts of interest to declare.

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