Unmet Needs of Patients Feeling Severely Affected by Multiple Sclerosis in Germany: A Qualitative Study

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Abstract

Background: The needs of patients feeling severely affected by multiple sclerosis (MS) have rarely been investigated. However this is essential information to know before care can be improved, including adding palliative care (PC) services where helpful. Since it remains unclear at what point specialized palliative care should begin for this patient group, this study focuses on needs in general.

Objective: The objective was to explore the subjectively unmet needs of patients feeling severely affected by MS.

Methods: The study used a qualitative cross-sectional approach for needs assessment. Fifteen patients self-reporting feeling severely affected by MS were recruited and interviewed using a combination of purposive and convenience sampling (five were accompanied by a caregiver relative). Interviews were recorded and transcribed verbatim, followed by qualitative content analysis.

Results: Unmet needs were identified in the main categories “support of family and friends,” “health care services,” “managing everyday life,” and “maintaining biographical continuity.” Patients expressed the desire for more support from their families and to be viewed as distinct individuals. They see a substantial deficit in the physician-patient relationship and in the coordination of services. A decrease in expressed unmet needs was found for patients more severely affected and less socially integrated.

Conclusions: To address the unmet needs of severely affected MS patients, health care services need to be improved and linked with existing PC services. Special attention is required to form supporting professional-patient relationships. Multiprofessional services should be accessible for patients, while integrating relatives. All services should have an individual approach to provide needs-tailored support.

Introduction

DESPITE NEW IMMUNOMODULATORY and multiple symptomatic treatment options, multiple sclerosis (MS) remains a chronic, incurable disease.¹ Many patients suffer from loss of multiple functions with severe physical and psychological implications leading to complex situations.²

Even though all patients with life limiting, progressive diseases are entitled to palliative care, only very few MS patients currently receive support from specialized palliative care.³ Palliative care appears to remain a counterintuitive

approach for MS patients.⁴ Needs assessment in this patient group is essential for designing a concept of intertwined palliative and routine neurological care for severely affected MS patients. As defining needs has proven highly complex,^{5,6} this study defines needs assessment as the assessment of subjectively perceived needs and preferences.^{5,6}

As it remains unclear at what point palliative care should begin for this patient group, the study focuses on unmet needs in general. From the outset it can be assumed that severely affected MS patients have a large variety of unmet needs. Our study aimed to identify the precise nature and range of these

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Accepted October 3, 2013.

Data from this study was presented in part in talks at the 10th EAPC Congress in Budapest, Hungary, June 7–9, 2007, and the 5th EAPC Research Forum in Trondheim, Norway, May 28–31, 2008.

unmet needs and to find out where palliative care could potentially be a valuable asset. In an effort to reveal unmet needs and match them to palliative care structures (or other health care services), our research focused on analyzing severely affected MS patients and their views, with them as the experts.

Needs assessment studies of MS patients can generally be found,^{7–10} but few focus on the experiences of this particularly vulnerable group of severely affected patients.^{11–14} Psychological support, occupational therapy, speech therapy, and palliative care for this group were all perceived as seriously deficient.¹⁵ It remains difficult to conduct adequate needs assessment, as there is still no single, unambiguous, clear definition for the term ‘severe MS.’¹⁶

The most commonly used instrument to evaluate the severity of affectedness, the EDSS (Expanded Disease Status Scale),¹⁷ assesses patients’ functional status, referring primarily to restriction of movement, not other symptoms relevant for the severity of MS (e.g., fatigue, depression, pain, visual dysfunction).^{18,19} Patients’ own subjective definitions of being severely affected fit with the palliative approach, where intervention is guided by the subjective assessment of suffering.^{16,20} Our study addresses this by exploring the unmet needs of MS patients in Germany who reported feeling severely affected. Our study is part of a larger study on unmet needs.²⁰

Methods

Data collection

Recruiting followed a purposive sampling strategy, based on hypotheses about patient characteristics; but as only a limited number of severely affected MS patients were found who agreed to be interviewed, inclusion criteria were expanded to include any patients willing to participate, i.e., convenience sampling.^{21,22} Patients’ reporting feeling subjectively severely affected by MS regardless of physical state determined inclusion. Informed written consent was obtained, and ethical approval was granted by the University Hospital of Cologne (#06-191).

Health professionals (GPs, inpatient and outpatient neurologists, nurses, one MS clinic) in the Cologne area caring for persons suffering from MS were contacted via telephone/mail and asked to distribute a leaflet about the study among patients. Some patients were directly asked by health professionals, with consent obtained by us thereafter. The

interviewer (MG) discussed participation during rounds. In total, 15 of 22 patients consented.

Episodic face-to-face interviews allowed for narratives (episodic knowledge) and for focusing on certain topics (semantic knowledge).^{23,24} The interview guide (see Table 1) was adapted for use by a trained sociologist (MG) working as a researcher within the department having experience interviewing palliative care patients as well as professionals. Prior to the interview, all participants received information on the study and were informed about the position of the interviewer, with whom they had no previous relationship.

Interviews were carried out at home (4) and on the neurology ward (11). Five patients chose to be accompanied by a caregiver relative whose contributions were also included in data analysis.

All interviews were recorded and transcribed verbatim, but not returned to the respondents for checking. Field notes were also made. Reasons for nonparticipation/refusal were not documented.

Interview quotes were translated by a native speaker and colloquial English used for colloquial German expressions. Interviews ranged from 25 minutes to 2 hours. Socio-demographic and disease-specific information was collected using a short questionnaire including a self-developed, non-validated scale for rating the extent of feeling severely affected by MS (1–10, 1 not at all, 10 totally affected). Respondents were asked their EDSS score (0, normal neurological exam; 10, death due to MS).^{17,25}

Analysis

Starting with a global analysis,²⁶ the first interview subjected to the open coding process²⁷ was with a young, single patient (interview 3). Five other interviews were coded using constant comparison to reveal minimal and maximal contrasts (single versus married versus divorced; different relationships between spouses; older versus younger; suffering versus coping with the current situation). In the next step of qualitative content analysis (all 15 interviews),²⁸ emerging codes were constantly compared and similar content from different interviews combined into preliminary categories. Categories at a higher level of abstraction were needed in order to be applicable to the whole set of data. Both categories and subcategories were iteratively refined. In this process, interdisciplinary data and categories²⁹ were

TABLE 1. TOPICS OF INTERVIEW GUIDE

<i>Topic</i>	<i>Examples of questions</i>
Current life situation and changes due to illness	We would like to ask you to tell us about how you are living with your illness at the moment.
Problems, burdens, and resources	What makes life with your illness difficult?
Label “being severely affected”	What does “being severely affected” mean for you?
Wishes, needs, expectations	What support or help would you like to receive? From your point of view are there any offers that could be helpful or offer relief in your situation?
Institutional and private parts of care	What do you expect from your relatives, your physician(s)/nurses, social workers?
Support for relatives/friends	Does your family/Do your friends need anything to cope better with your illness?
Association with palliative care/hospice attitude	What ideas do you have about palliative care/hospice? Under what conditions can you imagine using palliative care services/hospice for yourself?

discussed (MG, HG, UK) from sociological, neurological, and palliative care perspectives.

Our inductive approach also considered intercategory findings. Methodologically the study followed a grounded theory approach, restricted more to a description of identified needs than theory development.

Results

Sample I

All 15 patients who agreed to participate were included in the study due to the small total number of patients available. Of the 15 MS patients interviewed in November 2006, all considering themselves severely affected and are summarized in Table 2. Subjective affectedness ranged from 4 to 10 (mean 6.8), physical status from 3 to 9 (mean 6.5) on the EDSS. Time between diagnosis and interview varied from 4 to 41 years. Eleven patients were hospitalized for immunosuppressive therapy or comorbidities, such as infections. Table 4 illustrates patients' relationship to the relative accompanying them and living situation.

Unmet needs II

Patient expressed unmet needs were classified into four main categories (see Fig. 1; exemplary quotes for selected categories are given in Table 3): support from family and friends, health care services, managing everyday life, and biographical continuity.

Support from family and friends

Almost all patients reported decreasing networks of friends over the course of their disease, mentioning a desire for more support from family and friends via more contact and understanding of the consequences of handicaps.

Some patients (interviews 3, 4, 5, and 8) reported an MS-related, very painful breakdown of a partnership (hypothesis 1).

Patients integrated into social networks of family and friends expressed a greater range of unmet needs than those less well integrated.

Six patients considered some needs of relatives unmet, mentioning the need for better information, (psychological) counseling, psychotherapy, and participation in medical decision making.

Health care services

This category contained the greatest portion of unmet needs.

Access to services. Patients indicated difficulties obtaining access to various services, expressing desires for reduced waiting times, shorter distances to specialists, home visits, and better access for the disabled and driving services.

Competence. Some patients had difficulty finding neurologists and family doctors perceived as competent in treating MS, as well as physicians they perceived as being up-to-date with the latest treatment options.

Treatment options. Participants expressed ideas about additional treatment options envisaged as helpful, especially

someone outside the family to talk with (a rare opportunity presented by the interview and appreciated by many). Four persons (interviews 2 and 6—males; interviews 7 and 5—females) explicitly expressed a need for psychotherapy or emotional/mental care (hypothesis 2). Crisis support, though required, was not received as expected (interview 3). This patient also wanted to be able to talk about palliative care services with his general health care providers (hypothesis 3). Almost all patients expressed hope for medicines that truly help or cure.

Physician-patient interaction. Dissatisfaction with the quality of physician-patient interaction was readily apparent: Patients want assistance in evaluating self-obtained information and counseling regarding further treatment options. Some patients desired improved skills among care providers when communicating bad news; they appreciated information delivered early and honestly alongside engagement in future decisions. Patients wanted to be viewed as distinct individuals, be more respected and listened to as well as handled with sensitivity.

Time. Too little time during doctor-patient conversations was an essential unmet need. Two patients (interviews 11 and 2) wished their homecare services schedule could be individualized in accordance with their changing needs.

Information. Patients wanted more information from their doctors on the disease, its course, treatment options, and various existing services.

Coordination and continuity of services. Because of the limitations imposed by MS, patients desired greater support in finding potentially useful services, particularly when entering a new phase of the illness trajectory, where this help is most needed. Two participants criticized the discontinuity of services between the different sectors (outpatient and inpatient).

Financing services. Obtaining reimbursement for travel expenses to appointments or subsidies for equipping vehicles for the disabled was mentioned and described as an ongoing struggle (interview 2).

Managing everyday life

In the category "Managing everyday life," unmet needs were mentioned in the subcategories of "Housekeeping" (aids and services at home to enable them to stay at home (interview 3) and "Accommodation" (adaptation to their physical needs).

Maintaining biographical continuity

Work. This subcategory was important for those who considered work an integral part of their identity. These patients suffered dramatically from their inability to continue working and forced retirement.

Leisure. It was difficult to find alternatives for activities patients enjoyed before onset of their illness, like sports or travelling.

TABLE 2. BACKGROUND INFORMATION ON INTERVIEWEES

Interview	Sex	Age	Family status (a) Living situation (b)	Course of disease Time since diagnosis (in years)	Subjective affectedness	EDSS	Mental comorbidities (a) ^a Psychotherapy since diagnosis (b)	Occupation state ^b	Education ^c	Region
1	f	56	(a) Married (b) With family	Secondary progressive 26	8	8	(a) – no (b) – no	Retired	High school diploma	Rural
2	m	40	(a) Married (b) With family	Secondary progressive 11	6	7	(a) – no (b) – no	Full-time working	High school diploma	Urban
3	m	39	(a) Unmarried (b) Alone	Secondary progressive 5	8	6	(a) – yes (b) – yes	Retired	General qualification for university entrance	Urban
4	f	40	(a) Divorced (b) Alone	Unknown 8	4	Unknown	(a) – no (b) – no	Retired	High school diploma	Urban
5	f	43	(a) Married (b) Alone with son	Relapsing 6	7	6.5	(a) – yes (b) – yes	Full-time working	General qualification for university entrance	Rural
6	m	23	(a) Unmarried (b) Alone	Primary progressive 7	6	3	(a) – no (b) – no	Full-time working	General qualification for university entrance	Urban
7	f	35	(a) Married (b) With family	Relapsing 13	7	6	(a) – no (b) – no	Retired	General qualification for university entrance	Rural
8	f	36	(a) Unmarried (b) alone	Relapsing 5	6	6.5	(a) – no (b) – no	Unemployed	High school diploma	Urban
9	f	55	(a) Married (b) With family	Unknown 6	4	6.5	(a) – no (b) – no	Retired	(Qualified) school leaving exam	Rural
10	f	73	(a) Widowed (b) Alone	Primary progressive 9	7	7	(a) – yes (b) – no	Retired	No graduation	Urban
11	f	62	(a) Married (b) With family	Primary progressive 31	10	9	(a) – no (b) – no	Retired	High school diploma	Urban
12	m	62	(a) Married (b) Nursing home	Primary progressive 18	6	6.5	(a) – no (b) – yes	Retired	General qualification for university entrance	Urban
13	m	54	(a) Married (b) With family	Relapsing 22	8	Unknown	(a) – no (b) – no	Retired	(Qualified) school leaving exam	Rural
14	m	34	(a) Married (b) With family	Relapsing 8	5	5	(a) – no (b) – no	Full-time working	High school diploma	Rural
15	f	54	(a) Unmarried (b) Alone	Unknown 13	10	8.5	(a) – no (b) – no	Retired	(Qualified) school leaving exam	Rural
Mean (age) Median (EDSS/ affected-ness)		47			7	6.5				

^aSelf-report data.^bComment on occupational state: Reasons (age or disease) for retirement were not obtained.^cComment on education:High school diploma – German “*Realschulabschluss*” (10 years)General qualification for university entrance – German “*Abitur*” / (“*Fach*”-)*Hochschulreife*” (12 or 13 years)(Qualified) School leaving exam – German “*Hauptschulabschluss*” (9 years)

EDSS, Expanded Disease Status Scale.

TABLE 3. EXAMPLES OF QUOTATIONS FOR SELECTED CATEGORIES

Category	Subcategory	Interview	Quotation
Support of family and friends	Emotional support	11 479–484	“...a small circle of friends, because lots of friends have just gone and then they came back less frequently, but, at the end they stayed away altogether, because we aren’t much use for anything anyway. That’s the way it is. And the same even within the family. But we just have to put up with it.”
Health care services	Access to services	11 293–298	“At home we don’t get neurological treatment....At the very beginning it was a male neurologist...but later on he didn’t make home visits anymore, and on the third, fourth floor at the top there was a small spiral staircase.”
	Treatment options	7 538–546	“Now and then there was psychological support, just something, where you can really spill your guts out or something like that. Well now I’d rather not carry on whining. Because, uh, I don’t want to whine about it to my friends or my husband, he gets enough of how shitty it is sometimes. Or also how good it is sometimes in between. Uh, yes, just talking as a bit of support, that’d be nice.”
	Physician-patient interaction	6 473–477	“Uh, those are pretty private things, just things like attitude towards life or further progress or whatever, and all these are things you can talk about for hours, and I think that’s why the doctor doesn’t even bother getting into all that. Instead it’s just acute problems, and that was it.”
Maintaining biographical continuity	Work	13 41–43	“In the course of my life, I...had to stop working, I couldn’t do it anymore. Generally speaking, it’s bad enough that I’ll never be able to work again.”
	Leisure	14 54–57	“I would say that it’s basically the active stuff that’s changed. And that’s what I really miss most.”
	Leisure	14 88–89	“Yes, the most stressful thing is that I can’t do what I used to do any more.”
	Meaning/identity	8 132–141	“How can I explain this, I just happen to be known as a tough woman. And I’m also known in the neighborhood, to...everyone in the street, and I secluded myself, I just stayed in bed and didn’t do anything at all.... Because I was embarrassed, so, along the lines of, huh, there she is, the one we used to look up to, huh, so super and classy, all the things she does, and now suddenly there she is, crawling on all fours.”
	Societal acceptance	5 683–686	“...and just in public life, so wheelchairs can just go anywhere, knowing that wherever you go there is a toilet with wheelchair access or you can drive in at ground level.”

Meaning/identity. Coping with the loss of parts of one’s identity is often very difficult. Patients need to accept a changed “self” and attempt to regain meaning to their lives (hypothesis 2).

Societal acceptance. The expressed wish to not be excluded was related to patients’ desire to not be overly stigmatized and also to be better understood by the public (hypothesis 4). Public space should be better adapted for wheelchairs to ensure that people with disabilities are not excluded from public life (hypothesis 4).

Severity of disease III

Three interviewees had an EDSS of 8 or higher, and shared a great need to improve their basic physical state. Two persons’ (interviews 1 and 15) greatest wish was to somehow be able to go and to stand up (hypothesis 5). Other unmet needs were mentioned in which both interviewees (interviews 11 and 15) had radically reduced social networks and only one primary contact person (hypothesis 6).

It contrasts with interview 1 where a broad range of unmet needs was mentioned. This woman was more socially integrated and still had an interest in social contact even outside her family (hypothesis 6). Patients who were younger and had lower EDSS scores spoke more about their self development (hypothesis 5).

Discussion

The results of the study illustrate that patients feeling severely affected have a broad range of unmet needs that surpass the physical domains.

EDSS scores were moderate, median 6.5 Given that inclusion was via patient’s subjective feeling of being severely affected, connected with losses and changes for all interviewees,^{12,16} this is not unexpected. These findings support considering dimensions beyond those comprised in the EDSS.^{16,20}

TABLE 4. RELATIONSHIP OF PERSON CHOSEN TO BE PRESENT TO THE FIVE PATIENTS

Interview ^a	Relation to relative	Relative living with the MS patient
1	Husband (partly present)	Yes
2	Wife	Yes
4	Partner (partly present)	No
11	Husband	Yes
15	Sister	No

^aThe other interviewees had no relative present.

FIG. 1. Spell Categories of unmet needs of severely affected MS patients.

As severity of the disease progresses, patient needs appear to shift from concerns about the self on the level of self development to the very existential needs of one's physical state, corresponding to Maslow's classical hierarchy of needs.^{30,31} Subsequent losses due to the ongoing disease and accompanying processes of social exclusion with lack of close relationships can lead to a concentration on basic needs. The greater range of expressed unmet needs among less severely affected patients contrasts with the fewer unmet needs expressed by more severely affected individuals. Perhaps personal relationships can be a resource for those more severely affected, which then mediates the shift of needs or influences the ability to express one's needs, as in interview 1 (hypotheses 5 and 6). Whether this indicates less suffering when people with a higher EDSS express less or basic unmet needs, or is also connected with depression³² remains unclear. If so, the study by Arnett and colleagues³³ underscores the importance of good social support and positive self conceptions as protection against depression among MS patients, which should be considered for further investigation.

Relationships with family and friends appear to be exceptionally important, so early help for preserving family structures should be offered, at least to the most vulnerable families.^{34–37} Professional support for patients and for family and friends can reduce the burden on both.^{35,38,39} Empathetic physicians, nurses, and/or social workers may offer support in coping with MS and its consequences. Extant structures seldom provide psychological support, although the psychological impact of MS is a key issue for patients.^{8,14,40} This is underscored by the numerous unmet needs in the category "Biographical continuity;" most demonstrably the permanent threat of losing parts of one's identity.¹¹ Patients' expressed need to remain employed corresponds with previous findings.^{10,12,14} Losses of integral parts of identity (work, body function, hobbies, etc.) can produce personal crises^{10,14} and constant adjustment is needed.¹⁰ Early help with broadening individual strategies for maintaining biographical continuity could positively influence later phases of the illness trajectory.^{42,43} Changes in everyday life affecting

identity should also be part of counseling, as this requires constant renegotiation and adaptation.⁴⁵

Coordination in the health care system can be beneficial in consultations regarding managing everyday life. This includes continuity of services among different sectors and care professionals. The effectiveness of a coordinator for severely ill MS patients has to be proven⁴⁶ to address this deficiency.^{10,13,14}

Access to health care services tailored to individual needs (individualized homecare services schedules) remains a highly significant unmet need in this category. This sizeable deficit perceived in the physician-patient relationship was somewhat unexpected. Health professionals must offer patients emotional support and information to help them cope with a changed life perspective.^{47,48}

Closely intertwined with this is the unmet need for information about what services are available and what could be useful in the actual situation even if not noticed by professionals.^{13,14}

Role of palliative care in service improvement

The unmet needs identified in our study make it apparent that improved health care services are needed, along with a framework design of collaborating services. Improvements can be made at four levels:

- (1) A more sensitive approach by the existing services.
- (2) Functional integration of the palliative concept with neurology and rehabilitation. This implies recognizing and treating the individual as a whole biopsychosocial-spiritual human being and integrating relatives into total patient care. The multiprofessional palliative care team can help to meet diverse unmet needs which also implies that sufficient time be taken for professional-patient relations and coordination between the different professions and services.
- (3) Specialized palliative care should become part of a comprehensive concept for MS patients when necessary due to the complexity of the symptoms. The novel palliative service for MS developed and eval-

uated by Higginson and colleagues^{49–51} can be taken as a model for this idea.

- (4) Networking between extant MS patient-related health care services and application of a palliative approach will contribute to greater patient well-being and better quality of life for MS patients feeling severely affected. This suggests that health professionals from different professions must be willing to work side by side to create a space for exchanging experiences supported by coordination.

Limitations and strengths of the study

The interviews in our study were not conducted to theoretical saturation, with just 22 eligible patients having been asked to participate, 15 of whom agreed. This small number can be viewed as a critical limitation. All 15 patients were invited for interviews and all were included due to the small number participating. Recruiting patients for palliative care research is notably difficult^{52,53} and our study was no exception, as many severely affected MS patients seemed to be obscured or lost somewhere in the health care system. The limited available population represents a weakness of the study, restricting the extent to which the unmet needs encountered in our study cannot be generalized to all patients feeling severely affected by MS in Germany.

There are inherent barriers to conducting interviews with advanced MS patients, and only persons able to speak were interviewed. Cognitive impairments and depression further added to the difficulty of conducting the narrative portion in some interviews.

As the patients in the study indicated the severity of their condition themselves, there may also be an overrepresentation of MS patients self-reporting psychiatric comorbidities, introducing a potential source of bias in interpreting our data. Forms of diseases could not be reliably assessed, as not all patients could give precise descriptions, though patterns of unmet needs can be assumed to differ among these groups.

Having a relative present during the interviews may constitute another possible source of bias pertaining to patients' expressed needs, given that some of the needs investigated concerned the MS patient's relationship to his or her family.

As this is a cross-sectional study, there is little information about the dynamic changes of unmet needs within an ongoing illness trajectory. Greater insight may be found in longitudinal or qualitative studies focusing more on the illness trajectory.

The predominant strength of our study is that the participants themselves decided what was important in their own situation. So, in line with the subjectivity of symptoms, patients were included based on feeling severely affected. The qualitative approach allowed interviewees to express their views using their own relevance system, neither tailoring nor filtering the expression of their unmet needs to what is traditionally part of health care services. All interviews were conducted by a single, trained qualitative researcher.

Conclusions

When caring for severely affected MS patients, a multi-professional approach addressing both patients' and their relatives' needs is needed. Special attention should be given to supporting professional-patient relationships and to inte-

grating relatives, as the importance of family and friends for patients to express unmet needs has been emphasized. The coordination of different services is highly significant. All services should make an individual assessment of unmet needs in order to provide needs tailored support.

Author Disclosure Statement

No competing financial interests exist.

Acknowledgments

This study was supported by a grant from the "Ge-meynnützige Hertie-Stiftung" (grant #1.01.1/06/009). The clinical and academic activities of the Department of Palliative Medicine, University Hospital of Cologne, are substantially supported by German Cancer Aid (Deutsche Krebshilfe e.V.) as well as by the Federal Ministry of Education and Research (BMBF01KN0706). Patient sequences were translated by Kern AG, Cologne. We would like to thank all patients and their families who participated in this study and the German MS Society, especially Mrs. D. Pitschnau-Michel, for supporting our interest in this topic.

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