

A palliative care hotline for multiple sclerosis: A pilot feasibility study

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ABSTRACT

Objective: Research findings suggest that patients severely affected by multiple sclerosis benefit from palliative care. Our objectives were to (1) implement a pilot palliative care counseling hotline for severely affected multiple sclerosis patients and their caregivers in order to connect them to palliative care, and (2) evaluate its preliminary feasibility through a pilot study.

Method: The hotline was designed in cooperation with the local state association of the German Multiple Sclerosis Society and based on a review of the literature. The initial study setting for the hotline was the broader region of the cities Cologne and Bonn in Germany. The hotline was introduced through a magazine published by the German Multiple Sclerosis Society and leaflets sent to local healthcare providers. Calls were conducted using a semistructured interview guide and documented by a standardized case report form. Measures to assess feasibility were both quantitative (e.g., number of calls) and qualitative (e.g., criteria for eligibility for palliative care).

Results: During its pilot year, the hotline received 18 calls. Some 15 callers were included in the analysis, and 10 of these 15 were deemed eligible for palliative care due to such criteria as medical characteristics, care or nursing conditions, caregiver strain, and concerns regarding death and dying. Access to palliative care services could be provided for all 10 callers.

Significance of results: Based on our pilot feasibility study, the hotline seems to be a valuable service for patients severely affected by multiple sclerosis (MS) and their caregivers in order to gain information about and access to palliative care. It will be extended on a nationwide scale through a grant of the German Multiple Sclerosis Society. Awareness of the hotline needs to be enhanced in order to attract and support a significant number of new callers.

KEYWORDS: Palliative care, Severely affected by multiple sclerosis, Patient counseling, Hotline

INTRODUCTION

In Germany, approximately 120,000 patients are suffering from multiple sclerosis (MS) (Heigl et al., 2009). However, no such estimation exists for the number of *severely affected* MS patients. The number

and severity of symptoms in severe MS are comparable to those for advanced cancer (Higginson et al., 2006). Nevertheless, palliative care (PC) in Germany is still predominantly focused on cancer patients (Ostgathe et al., 2011), and a palliative care approach for MS patients is mainly regarded as counterintuitive (Golla et al., 2014). Against the common notion that MS is not a lethal disease, MS can indeed lead to death (Ragonese et al., 2010; Sumelahti et al., 2010), and severely affected MS patients are

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interested in communicating about death and dying (Buecken et al., 2012).

Conventional healthcare services for MS do not necessarily address all of a patient's needs (Kuempfel et al., 2007), and there are first indications that palliative care can be a valuable complementary asset (Higginson et al., 2008; Edmonds et al., 2010). In order to bring patients severely affected by MS into contact with PC, we established a PC counseling hotline dedicated to MS. A hotline allows for consultation that does not require a patient to leave his home. We chose a telephone hotline over the use of an informational website. Hardyman and coworkers (2005) found that cancer patients primarily utilized such a website to get factual information, whereas an accompanying hotline was employed to discuss emotionally complicated issues. It can be assumed that seeking information about PC may be such a charged and complicated issue, since PC may be associated with unsettling emotions (Boldt et al., 2006; Fadul et al., 2009; Kierner et al., 2010). A review revealed that medical counseling hotlines usually yield high degrees of caller satisfaction and acceptance (Byers et al., 2002).

The aims of our study were to (1) develop and implement a pilot PC counseling hotline for severely affected MS patients and their (in)formal caregivers, and (2) test its preliminary feasibility through a pilot study.

METHODS

Development of the Hotline's Concept

We collaborated with the German Multiple Sclerosis Society (Deutsche Multiple Sklerose Gesellschaft; DMSG) as experts in the field who already offer a nationwide MS helpline. This helpline, however, was not specifically targeted at *severely affected* MS patients and their caregivers who may have PC needs (Edmonds et al., 2010; Golla et al., 2012; Galushko et al., 2014). Our pilot PC counseling hotline thus aimed to serve as an additional service. We reviewed the literature to gain insight into the best practices for conducting calls (Wahlberg & Wredling, 2001; Byers et al., 2002; Silverman et al., 2005; Moscato et al., 2007; Beaulieu & Humphreys, 2008; Derkx et al., 2009).

Participants and Settings

The participants targeted for our hotline were patients severely affected by MS as well as their (in)formal caregivers. We did not give a definition of "severely affected by MS," but left it to the patients to decide whether or not they fit this description

(Galushko et al., 2014). In accordance with the principles of PC, we intended to avoid disregarding patients' self-assessments through an explicit definition. Moreover, subjective affectedness has been shown to correlate with disability (Strupp et al., 2012), captured by the Expanded Disability Status Scale (Kurtzke, 1983).

The study setting for testing the pilot hotline's feasibility was the broader region of the cities of Cologne and Bonn (4.3 million inhabitants, approximately 5% of the total population of Germany), which is well equipped with various inpatient and outpatient PC services (see Table 1). The setting was extended to the cities of Aachen and Düsseldorf from January of 2012 until May of 2012. Again, both cities are relatively well equipped with PC structures. The total number of inhabitants in the study setting thus rose to 5 million.

Introducing the Hotline to the MS Community

The hotline was introduced through an article in the patient magazine "MS-Magazin" published by the local state association of the DMSG. A permanent online version of this article could also be found and read online at the website of a local DMSG branch. Additionally, we sent leaflets to a convenience sample of formal MS caregivers (MS healthcare centers, neurologists, physical therapists, occupational therapists, speech therapists, urologists and general practitioners) and MS self-help groups in the study setting asking them to distribute them among MS patients. The hotline's extension to Düsseldorf and Aachen was again publicized in a short article in the DMSG magazine, and leaflets were sent to general practitioners in the two cities. A total of 3000 leaflets were sent out.

Concept of the Hotline (Intervention)

Aims and Services of the Hotline

Table 1. Number of available palliative care services in initial study setting

Available Services	<i>n</i>
Palliative care units	5
Specialized outpatient palliative care teams*	2
Nursing services providing palliative care	19
Physicians specialized in palliative care	33
Hospices	10
Voluntary community hospice services	55

*For definitions of terms, see the glossary in the Appendix.

Our pilot PC counseling hotline aimed to serve as a bridge between palliative care and severely affected MS patients along with their (in)formal caregivers by

- a. discussing the caller's individual situation in order to assess the caller's eligibility for PC, and to clarify what specific service of PC would be most helpful
- b. providing information about PC
- c. providing access to PC by recommending available local PC services

Office Hours of the Hotline

From June of 2011 until January of 2012, the office hours of the hotline were Monday to Thursday from 4:00 to 6:00 p.m. Along with the extension of the hotline's service area in January of 2012, we changed the office hours to Monday and Thursday from 10:00 a.m. to 1:00 p.m., and 2:00–6:00 p.m. to provide an additional opportunity for morning calls.

Conduction of Calls and Data Collection

The operator (AK) attended a two-day seminar in client-centered communication technique (Rogers, 1965), which is recommended for such hotlines (Byers et al., 2002; Beaulieu & Humphreys, 2008). Being authentic with respect to the nature of palliative care, the availability of PC services, and the possible boundaries connected to the consultation, we sought to encourage callers' confidence in the operator and her consultation. With respect to offering a well-structured consultation and to provide an orientation tool for the hotline operator, we developed a semistructured interview guide (Figure 1) inspired by the Calgary Cambridge Guideline (Silverman et al., 2005).

Sociodemographic and disease-related information as well as concerns regarding death and dying, including the wish for hastened death and suicidal ideations, were collected by a standardized case report form and field notes. The data were pseudonymized using a code for each caller.

CCG	Hotline Procedure	Aim(s)
Initiation	1a. Introducing staff & greeting the caller 1b. Asking for caller's request	Building a positive relationship
Gathering information & building the relationship	Reconstructing the caller's current life situation using client-centered communication technique	<ul style="list-style-type: none"> ▪ Maintaining a positive relationship ▪ Gathering information for step 3d
Structuring the interview	3a. Summarizing the caller's narration 3b. Checking for narration's completeness through additional questions (if necessary) 3c. Clarifying caller's most important needs 3d. Deciding if PC is the appropriate intervention for the caller's situation: <ul style="list-style-type: none"> ▪ If no: clarifying why PC is not suitable and providing contact to more adept experts (e.g., DMSG helpline) ▪ If yes: describing briefly the following steps of conversation 	Gathering information for step 3d <ul style="list-style-type: none"> ▪ If no: avoiding to make caller feel that there is no support ▪ If yes: giving an idea to the caller which expectations may be met by the consultation (and which not)
Explanation and planning	4a. Describing PC briefly 4b. Describing concrete options of PC tailored to caller's situation 4c. Instructing the caller how PC needs to be prescribed through the caller's current family doctor 4d. If desired: recommending available local PC services to caller	Providing information about PC Clarifying the extent to which PC could be helpful for the caller's individual situation Enabling caller to contact and involve PC
Closing	5a. Checking for caller's comprehension of information 5b. Checking for open questions of caller	Checking that provision of information about PC succeeded

Fig. 1. Interview form in the style of the Calgary Cambridge Guide (CCG).

Evaluation of the Feasibility of the Hotline's Concept

Feasibility Objectives and Criteria

One main objective of our study was to test the preliminary feasibility of the hotline through a pilot feasibility study. Feasibility objectives along with criteria for assessing their success are shown in [Table 2](#).

Sampling

The sample included all callers who contacted the hotline during the pilot phase between June 1, 2011 and May 31, 2012 (convenience sampling).

Inclusion/Exclusion Criteria

Callers were included in the analysis if (1) the caller was either an MS patient or an (in)formal caregiver of such, and (2) the caller provided sufficient information for an assessment of eligibility for PC based on criteria including medical characteristics, conditions of care and nursing, caregiver strain, and concerns regarding death and dying. Callers were excluded from analysis if they (1) did not meet the inclusion criteria or (2) did not ask for help with a specific case.

Data Analysis

The success of the pilot study was analyzed descriptively according to the criteria shown in [Table 2](#).

Ethical Committee Approval

This study received approval from the ethical committee at the University of Cologne (application no. 11-111).

RESULTS

The results are presented according to the pilot study's objectives (see [Table 2](#)).

Participants and Setting

During its pilot year, the hotline had 18 callers. Three callers (#5, 10, 13) had to be excluded from analysis due to exclusion criteria: 1 neurologist who did not provide sufficient information about his patient, 1 director of a self-help group who asked for leaflets for patients, and 1 physiotherapist who wanted to learn more about the hotline's mission. Three of the remaining 15 callers called from outside of the study setting (# 14–16), but we decided to include them in the analysis because of the low number of callers. Due to this low number, the monthly and daily rates of calls were not determined.

The remaining 15 callers included 11 patients (8 female) and 4 informal caregivers (3 female).

Some 7 of these 15 callers explicitly asked for PC (e.g., "What can PC do to relieve my suffering?"), and 6 were in fact deemed eligible for PC (# 7, 9, 11, 15–17). Four callers did not explicitly ask for PC (e.g., "I would love to take my severely disabled wife out, but we have no car"), but described a scenario eligible for PC later in the conversation. All of them were considered eligible for PC (# 2–4, 6). The remaining four callers were not considered eligible for PC due to queries that were irrelevant for PC (e.g., "Can arthritis move from my ankles into my legs?"). These callers were given the contact information for more suitable providers. The mean duration of calls of eligible callers (# 2–4, 6, 7, 9, 11, 15–17) was 35.2 minutes (range, 15–70), versus 20.6 minutes (range, 10–30) with ineligible callers (#1, 8, 12, 14, 18).

Aims and Services of the Hotline

Assess Callers' Eligibility for PC

[Table 3](#) shows the available medical characteristics of the 10 patients eligible for PC. With respect to care and nursing conditions, two patients (# 11, 15) were cared for at an intensive care unit at the time of the call due to severe complications such as infections. One patient (# 9) lived in a nursing home. Five of the remaining seven patients living at home were cared for by their spouses (# 4, 6, 7, 16, 17). Two of these (# 6, 17) needed significant assistance with personal hygiene and food intake. Due to financial problems, the family could only afford a nursing service once a week, so that the husbands were providing most of the care. Both husbands were elderly men who were themselves suffering from various ailments.

Four informal caregivers expressed that they (caregiver and patient) came to believe that death might be a possible impending outcome of the disease (# 6, 9, 11, 15). The caregivers stated that they felt both practically and emotionally overwhelmed by the implied responsibilities, including advance care planning and decision making. Three caregivers reported their patient's wish for a hastened death, which in two cases had taken the form of concrete suicidal intentions (# 9, 15), including one suicide attempt (# 15).

Provide Information About PC

If a caller's situation was considered to make them eligible for PC, the caller was given a brief description of palliative care. All 10 callers were interested in learning about PC, about what specific PC service might be helpful for their individual concerns, and how they could access it.

Table 2. Feasibility objectives and criteria for success of feasibility

	Feasibility Objectives	Criteria for Assessing Success of Feasibility
Participants and setting	How high is the general demand for the hotline (in the study setting)?	Number of overall/monthly/daily callers
	How high is the demand with respect to the specific PC nature of the hotline (in the study setting)?	Number of queries directed to PC
Aims and services of the hotline	Assess caller's eligibility for PC: Can eligibility for PC be assessed over the phone?	Yes/no? <ul style="list-style-type: none"> ■ If yes: what are criteria for eligibility? ■ If yes: duration of calls?
	Provide information about PC: Is there a need for information about PC?	Number of callers who are interested in learning about PC
	Provide access to PC:	
	1. How high is the demand for access to PC?	1. Number of callers asking for access to PC
	2. Can this demand be met by appropriate available services?	2a. Number of callers for whom an appropriate PC service can be provided
	3. What PC services are most needed?	2b. Number of callers for whom appropriate of PC services are lacking 3. PC services that are most needed
Introduction of the hotline	What means of introduction is most effective? <ol style="list-style-type: none"> 1. Article in DMSG magazine 2. Online version of the article 3. Leaflets 	Number of callers who learned about the hotline through article/online version of article/leaflets
Office hours of hotline	What are the most economic days on which to run the hotline in terms of highest demand?	Days of week that receive most callers
Conduction of calls	Client-centered communication technique: Are Roger's concepts of empathic understanding, unconditional regard, and authenticity feasible for consultation about PC? Interview guide: Is it feasible for: <ol style="list-style-type: none"> 1. structuring calls 2. providing orientation for operator 	Subjective assessment through operator: if the client-centered communication technique and the interview guide were helpful in yielding the desired effects: <ul style="list-style-type: none"> ■ candid and trustful communication ■ well-structured calls ■ orientation for the operator

Table 3. Medical information about the patients

Call No.	2	3	4	6	7	9	11	15	16	17
Sex of patient	F	F	F	F	M	F	F	F	F	F
Duration of MS in years	ND ^a	>25	ND	16	ND	15	30	1.5	ND	32
Type of MS	ND	ND	Progressive type	SPMS ^b	ND	PPMS ^c	SPMS	Being clarified	ND	Progressive type
Symptoms (M = 4.55, SD = 3.05)	Pain Spasms Spasticity	Pain	Due to leukemia (not reported here)	Dysarthria, Dysphagia, Dyspnea, Neuropathic pain, Slight disorders, Spasticity, Tetraplegia	Loss of function of left hand, Pain, Spasms	Hyperesthesia, Incontinence, Insomnia, Loss of appetite, Muscle cramps, Neuropathic pain, Spasticity, Tetraplegia	Anarthria, Dysphagia, Cognitive impairments, Incontinence	Dysphagia, Hemiparesis (right), Hemiplegia (left), Nausea, Slight disorders, Vertigo, Vomitus	None	Bladder and bowel problems, Decubitus, Dysarthria, Fatigue, Joint pain, Loss of trunk control, Memory disorder, Tetraparesis
Complications	None	None	Due to leukemia (not reported here)	Constipation	None	Underweight (< 100 lb)	Pneumonia	Perhaps cancer (being clarified at time of call)	None	Recurrent infections

^aND = no data.
^bSPMS = secondary progressive MS.
^cPPMS = primary progressive MS.

Table 4. Recommended palliative care services

Recommended Services	Number	Call No.
Palliative care units	3	6, 9, 17
Specialized outpatient PC teams	1	4
Nursing services providing PC	2	2, 7
Physicians specialized in PC	2	3, 7
Hospices	-	-
Voluntary community hospice services	-	-
Local PC network	2	15, 16
PC consultation service of hospital	1	11

Providing Access to PC

Recommendations for available PC services in the patient's area could be provided in all 10 cases (Table 4).

Two callers from outside the study setting (# 15, 16) were encouraged to contact their local PC networks to learn more about available PC services in their hometowns. One family (# 11) had to decide between intensive care and PC for the patient, and it was recommended that they seek consultation from the hospital's PC consultation service. Due to the yet limited availability of specialized outpatient PC teams, this service could not be offered to three patients (# 6, 7, 9) who were deemed eligible for it. Alternatively, these patients were encouraged to stay at a PC unit (# 6, 9) or involve a PC physician and a PC nursing service (# 7).

Introduction of the Hotline

Five callers learned about the hotline through the article in the magazine published by the DMSG (# 1-3, 16, 17), and two callers found and read this article online (# 9, 11). Four calls were prompted by our leaflets (# 6, 7, 12, 15). The remaining four calls did not provide an opportunity to ask how callers learned about the hotline.

Office Hours of the Hotline

Six callers called on a Monday (# 1-3, 14, 15, 17), five on a Tuesday (# 6-9, 11), and four on a Thursday (# 4, 12, 16, 18).

Tools and Procedures for Conduct of Calls

Rogers's client-centered communication technique seemed to be particularly helpful for identifying PC needs that were not explicitly addressed by callers (# 2-4, 6). The interview guide in the style of the Calgary Cambridge guideline (Silverman et al., 2005) was a useful tool for the operator to structure and keep track of the course of conversations.

DISCUSSION

To our knowledge, our pilot PC counseling hotline for multiple sclerosis was the first of its kind. What are the possible reasons for the small number of callers? Due to lacking records on the number of (severely affected) MS patients, the number of potential callers could not be estimated in advance. A qualitative study by our department (Golla et al., 2014) indicated that MS patients do not know what PC is or, if they do, associate it with cancer and dying. Consequently, MS patients may have not felt addressed by the hotline or may have felt reluctant to call. Some studies argue that the language used to introduce PC plays a crucial role as to whether PC is perceived positively (Boldt et al., 2006; McInturff & Harrington, 2011). Since we pretested neither the article nor the leaflet, the language employed in these materials may not have been optimally encouraging.

Moreover, the article in the DMSG magazine was only accessible to paying members of that organization. Our leaflets may not have been the optimal choice for introducing the hotline. Wenk and colleagues (1993) identified radio as the most powerful channel for introducing an Argentine PC hotline to cancer patients, eliciting 80% of all calls. Broadstock and Hill (1997), testing the impact of informational leaflets on promotion of a cancer helpline through cancer specialists, found that additional calls prompted by these leaflets accounted for only 4% of overall calls.

In contrast to Broadstock and Hill, we did not check whether physicians actually gave the leaflets to their patients. Possible reasons for their not doing so may be a misconception of PC as solely end-of-life care (McInturff & Harrington, 2011) or a fear of causing distress in their patients (Fadul et al., 2009; Kierner et al., 2010). German neurologists do not necessarily consider PC relevant for MS and doubt that PC can meet the complex needs of their patients (Golla et al., 2014). Some physicians may think that they are already providing good enough symptom management so that additional PC care is not required (Snow et al., 2009; Golla et al., 2014). It is, of course, also plausible that some of them did not have any severely affected MS patients.

The fact that informal caregivers called on behalf of the four most compromised patients (# 6, 9, 11 and 15) in our sample implies that severely affected MS patients are often unable to make this call. Our office hours may have posed another barrier to callers, as some days (e.g., on the weekend) and daytimes (e.g., evenings) were not available.

Despite the low number of callers, our pilot feasibility study suggests that the hotline is a valuable service for MS patients and their informal caregivers

once they do make the call. Preliminary eligibility for PC could be assessed over the phone and eligible patients (10 of 15) asked for access. This indicates that there was a need for PC among MS patients in this study that could be met by facilitating access through our hotline. If this trend found in our pilot feasibility study could be replicated on a larger scale, a considerable number of patients could benefit from the hotline. Based on this potential, the hotline will be extended to a nationwide scale through a grant from the DMSG.

In order to enhance its availability, the hotline should be advertised on television and/or radio in addition to previous means of introduction. Through such procedures, palliative care may reach a level of normalcy for multiple sclerosis patients, ideally arousing their interest already at an earlier stage in the disease. Palliative care may help prevent the severity of suffering that reportedly provoked some patients' wishes for a hastened death. By evaluating MS patients through a hotline, their quality of life and autonomy may be improved by providing PC services.

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CONFLICTS OF INTEREST

The authors state that they have no competing financial interests to declare.

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APPENDIX

Glossary of Definitions of Palliative Care Terms According to the German Society for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin, 2009)

Specialized outpatient PC Team

The goal of the team is to maintain patients' quality of life and autonomy as much as possible, providing a humane life in familiar surroundings (home but also nursing home or hospice) until death. Specialized outpatient PC teams serve patients, their families and healthcare providers when the intensity or complexity of problems caused by the disease requires short-term or long-term attention. This may involve pain and symptom control counseling, and coordination of required healthcare services including comprehensive individualized care and round-the-clock availability of a multi-professional team.

Voluntary community hospice services

Voluntary community hospice services provide trained volunteers offering individual support (e.g., spiritual support, assistance in daily activities, being there for the family etc.) for severely sick and dying patients and their families.