Value of a Confidant Relationship in Psychosocial Care of People with Multiple Sclerosis

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We explored the effects of living with multiple sclerosis (MS) on a primary relationship: that between the person with MS and his or her closest confidant. We anticipated that this would enhance understanding of the meaning of psychosocial support from the perspective of people with MS. Using a phenomenological qualitative approach, we interviewed 33 people with MS and the people they identified as providing psychosocial support to them (their confidants). The results were presented to a range of health-care workers in two focus groups to explore their responses. Two additional focus groups were held with the participants with MS to add depth and clarity to the findings. Three major themes emerged from the interviews: 1) People with MS do not want to be defined by their condition and want to live as normal a life as possible. 2) The confidant helps to maintain this sense of normality. 3) Both the person with MS and the confidant value the relationship and together try to manage the realities of living with MS. The findings indicate the need to raise awareness among MS care professionals about the value of the confidant relationship. Training professionals to discuss emotional issues with clients and increasing collaboration with agencies that provide emotional support will facilitate a more holistic approach to care. Int J MS Care. 2012;14:115–122.

The relationship between social support and emotional well-being has been well recognized, and researchers have called for further study to identify components of these two interrelated factors.¹ Relationships with confidants have been shown to have value and to improve well-being in people with acute medical conditions,² and it is reasonable to believe that this might also be the case for people with a long-term condition such as multiple sclerosis (MS). The term *confidant* was used in this study because it suggests emotional ties between two people that go beyond everyday physical care and encompass psychological, emotional, and social support.² While the majority of confidants are spouses, this primary emotional tie may also be with a friend, child, sibling, or partner.³

Background

The theoretical framework for this study was developed from two perspectives: relevant literature to support the need for the study and the use of a phenomenological perspective to understand the experience of living with MS. Phenomenology explores how people understand their world, from their perspective, and how they function in it.

Historically, health care has focused predominantly on the physical aspects of disease. Work investigating quality of life issues in people with MS has highlighted that clinicians tend to focus on physical manifestations of the disease, while patients tend to give priority to its emotional impact and effect on everyday living.⁴ However, recent research involving people with long-term conditions has reported a new emphasis on the need for psychosocial care.⁵ The importance of psychosocial care has also been highlighted in a range of government health and social policy documents focusing on long-term conditions,⁶ although the term *psychosocial care* has

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not been well defined. The evidence on which these documents are based is predominantly from the quantitative research paradigm; the need for qualitative studies to complement these data has been acknowledged. There have been various attempts to define the components of psychosocial care. While some focus on practical aspects such as service provision,⁷ others suggest that the individual's subjective assessment of social support is key.⁸ In this article we use the terms *emotional support* and *social support* to indicate the two facets of psychosocial care. We were interested in gathering the perspectives of people with MS and their confidants to enhance our understanding of the meaning of psychosocial care for those receiving it.

Two key concepts, related to the psychological adaptation to disease, are useful to consider here. The first is how a person with MS adapts to the diagnosis and disease symptoms in order to return to experiencing as normal a life as possible. "Feeling normal" has been identified as important in feeling part of society and maintaining quality of life.⁹ The second key concept relates to how a person manages the responses of others toward impairment and aspects of the environment that present challenges to those with disabilities. For example, reduced access to public buildings can affect a person's sense of well-being, which in turn challenges this sense of normality.¹⁰

The degree of psychosocial adjustment to the diagnosis of MS, and coping strategies to maintain the subjective sense of living normally, can depend on the availability of close relationships.³ Some researchers have proposed that people with preexisting strong personal relationships fare better than those without them. It has been suggested that it is the balance between existing emotional support, the development of relationships over time, and the degree to which professional caregivers can recognize, intervene, and offer appropriate information and care that improves the lived experience of disease.¹¹

We sought to undertake an in-depth exploration of the qualities of the relationship between the person with MS and his or her confidant in order to improve our understanding of the meaning of emotional and social support to people with MS, how that support functions over time, and its impact on managing the realities of living with MS. In doing so, we hoped to gain insights into whether this relationship might help health-care professionals to improve the provision of care.

Research Approach and Methods

A Heideggerian hermeneutic qualitative approach¹² was used. Heidegger's premise is that individuals "live-in-the-world," affect it, and are affected by it in both positive and negative ways. A phenomenological method allowed us to study the lived experience of MS, focusing on the anecdotes in the transcripts of interviews and focus groups with study participants that reflected how people with MS feel their disease affects their sense of place in the world. Hermeneutics aims to discover hidden meanings in phenomena and insights into why people behave the way they do. Therefore, this research approach allowed us to understand experience from the participant's point of view and then use that data to inform practice.

This study was conducted in two phases. Phase 1 consisted of gathering data from the perspectives of people with MS and their confidants, using in-depth interviews and focus groups. In phase 2, focus groups with health-care and social-services professionals were used to explore their perspectives on whether and how the supportive role played by confidants might be useful to those providing professional care. Results of the focus groups with these professionals will be reported elsewhere.

This study was approved by the South West Devon Research Ethics Committee, England, United Kingdom (REC Reference 06/Q2103/82).

Interviews

Qualitative interviews are appropriate when the research aim is to understand the nature of experience. In this study, individual in-depth interviews offered participants the opportunity to describe their experience of MS and reflect upon how, when, where, and by whom they felt emotionally supported. A topic guide, developed in collaboration with an advisory steering group, was used. The first author (JG) also kept a reflective diary in which, after each interview, she documented her reactions and responses and any issues that arose during the interview that might have affected the discourse.¹³

Focus Groups

Focus groups are widely used to exchange ideas and develop solutions to problems. Of particular relevance to this research, they have been shown to be useful in elucidating how people think about a particular problem and in encouraging them to challenge ideas through group interaction.¹⁴ Our intention was to actively encourage

this discussion so that we could assess the value of the confidant relationship both to people with MS and to health-care professionals.

Participant Selection

Criteria for participant selection were developed by an advisory steering committee of experienced MS clinicians comprising two neurologists, two MS specialist nurses, a person with MS, and two researchers. Purposive sampling was used to recruit a maximum-variation sample in terms of disability level, disease duration, sex, age, and type of MS. Excluded from the study was any person who had cognitive impairment to the extent that the person was unable to provide fully informed consent or would be unable to be fully involved in the research process. As part of our sampling strategy, we aimed to recruit people with MS who had a confidant as well as those who did not.

Consenting participants with MS were asked to identify the person they regarded as their confidant. The choice was left entirely to the participant, with no suggestions by the researchers. A convenient time and place for each interview was arranged. Separate interviews were similarly arranged for consenting confidants. Following analysis, all people with MS who had participated in the interviews ($n = 20$) were invited to one of two focus groups. Ten participants agreed to attend and consented to the focus group process. The reasons for nonparticipation included current MS relapse, fatigue, and the need for participants to travel to the venues where the focus groups were taking place (in contrast to the interviews, which were held in their own homes).

Data Collection

The individual in-depth interviews each lasted about 45 minutes. Twenty interviews were conducted with people with MS (13 with a confidant and 7 without). Separate individual interviews were conducted with the confidants ($n = 13$). All participants were interviewed in their own homes. A topic guide was used to enhance the narrative process. Initially participants were asked to relate their history from diagnosis, not only to provide some context for understanding the confidant relationship but also to give individuals the opportunity to relax and “tell their story.” Subsequent questions focused on the confidant relationship, specifically the definition of a confidant, reasons for choice of confidant if the person had one, and the reasons why the person felt psychologically and emotionally supported by the confidant.

A topic guide was also used for the interviews of the confidants (Table 1). All interviews were audiotaped and transcribed verbatim. Personal names and locations were changed to protect participant identity.

Following analysis of the interview data, two audiotaped focus groups lasting approximately 2 hours each were conducted with the people with MS ($n = 10$). Two focus groups were undertaken so that the participants, who were drawn from a wide geographic area, could get to a venue that was convenient for them. The makeup of the two groups was similar in terms of type of MS, degree of disability, and age range. Themes from the interview analysis were presented to participants, and they were encouraged to discuss their thoughts. Group interaction was facilitated to generate a broad range of ideas. The purpose of these focus groups was to determine whether and how the themes generated from the interviews truly and recognizably reflected the meaning of psychosocial support for the people with MS interviewed and how it was manifested in the confidant relationship.

Data Analysis

The analysis technique described by Holloway and Wheeler¹⁵ was used for both study phases. The primary researcher (JG) listened to the audiotapes of the interviews and focus groups. She made comments on the transcripts and then read and re-read them to identify significant words, metaphors, or sections that appeared to reflect the phenomenon of the psychosocial impact of MS, and particularly the confidant relationship. Where there was similarity of ideas, they were combined. Once all transcripts had been analyzed, a matrix was designed that enabled the emergence of initial themes. Once initial themes had been identified, they were re-analyzed by sorting them under overall theme headings.

Ensuring Rigor

The research process was managed using the criteria of credibility, transferability, and dependability.¹⁶ All steps were guided by the steering group, and a clear

Table 1. Topic guide for confidants

- Tell me about yourself.
- What is the role of a confidant?
- What did you feel when [the person with MS] named you as their confidant?
- How has it affected you? What are the ups? What are the downs?
- How do you see the future?

audit trail of decisions was recorded. These practices, coupled with the maximum-variation sampling method, provided credibility and transferability to the process. In addition, four transcripts were coded independently by two other researchers (HS and JF). Consensus through discussion was reached on the emerging themes. The steering group considered the themes and discussed their relevance. Early findings were presented at local MS research meetings to provide a further check that they reflected the broader experience of people with MS, as well as to maintain ongoing involvement of members of the local branches of the MS Society of Great Britain and Northern Ireland. The two focus groups held with people with MS who had participated in the study served to add depth and clarity to the identified themes and to confirm the dependability of the interview findings.

Findings

Demographic and Diagnostic Characteristics

Of the 20 people with MS interviewed, 13 (65%) were female. The age range was 30 to 80 years. A total of 11 (55%) were married, and in terms of occupational status 3 (15%) were employed, 14 (70%) were receiving sickness benefits, and 3 (15%) were retired. These characteristics are reflective of the general demographic profile of individuals with MS.

The range of time since diagnosis was 6 months to 28 years (mean, 12 years). With regard to type of MS, 1 person had benign MS, 10 had relapsing-remitting disease (2 were in a relapse phase at the time of the interview), and 9 had progressive MS (6 primary progressive and 3 secondary progressive). The spectrum of disability was broad, ranging from the presence of minimal symptoms to severe disability requiring the person to be dependent on a wheelchair and to rely on others for the majority of their daily care.

Of the 13 people who had a confidant, 7 (54%) were married to that person. Of the 7 people who described themselves as having no confidant, 4 (57%) were female and 3 (43%) were male; only 1 of the 7 people, a female, was married. Eight of the 13 confidants (62%) were female.

Definition of a Confidant

The people with MS interviewed had no difficulty in describing the role their chosen confidant played in their lives: "sharing everything with somebody that you feel safe with . . . having somebody who understands

you, and has empathy" (female person with MS); "humanity without the fuss" (female person with MS). It also appeared that the relationship was reciprocal, with the confidant also benefiting: "It's a nice feeling, quite special, not just a normal husband or wife" (male confidant).

Themes

The three main themes that emerged were labeled *normality*, which describes the MS patient's desired default position; *supportive collusion*, which describes the nature of the confidant relationship; and *facing reality*, which describes the role the person with MS and the confidant developed to maintain a sense of normality.

Normality

The participants described the importance of feeling normal and not being defined by their disease. This involved removing MS as the central focus of their lives: "We're not absolutely different from other people just because we have MS. We do other things just as normal . . . in reality we're all human beings, we love, we hate, we argue, we have to go to work, so it's only part of our lives. . . ." (male person with MS).

Supportive Collusion

The role of the confidant related strongly to the need of the person with MS to feel normal, and the confidants recognized this role. The confidant and the person with MS appeared to have an unspoken understanding about how to manage the symptoms of MS to enable the person to live as normal a life as possible. We chose the word *collusion* purposefully because, despite the term's negative undertones, it reflects the tacit agreement by the person with MS and the confidant to support each other and try to maintain normality while being constantly bombarded by others with reminders of the disease and the limitations it imposes: "We don't talk about it . . . it's as if we have an understanding . . . he'll help me out but he won't say anything and I don't argue with him and say 'I can do it myself' because I know I can't. And he instinctively knows when I need help and he doesn't help when I don't need help" (female person with MS). "The fact that you don't have to think three times before saying anything . . . it's the trust, it's the understanding, the fact that I understand [confidant] and she understands the way I work . . . you don't have to be careful" (female person with MS).

The confidants described many steps they took to make this type of relationship possible. One example

was educating themselves about MS in order to be able to have informed discussions with the person with MS if desired. This preparedness was recognized as a positive form of collusion: “If a problem comes up we do discuss it obviously . . . but I don’t think it’s something you want to talk about all the time. You just have to get on with it and see how it goes” (female confidant). There were, however, occasions when the symptoms of MS had to be dealt with first before other activities could be undertaken. For example, the confidant would plan ahead and organize transportation and adapt physical surroundings to meet the needs of the person with MS. The key to the success of this approach was that the person with MS was not made aware of the constant planning on his or her behalf, thereby enabling maintenance of a sense of control: “When she comes in here I get the pillows because this [the sofa] is obviously not good when she’s having a relapse. Erm, but if she’s able to come out with a stick I just, you know, do what I can do to make her comfortable when she’s here” (female confidant).

The role of the confidant was therefore to be aware of the emotional and physical needs of the person with MS and to anticipate what had to be done. The confidant felt no need to point out what he or she was doing. The confidant also protected the person with MS from others’ attempts to draw attention to the disease. This was sometimes extremely difficult and caused the confidant some anxiety: “I feel like reacting quite strongly to the way people treat her because she looks OK [people’s expectations of her function are high]. She’d be much better if she was hobbling around with a stick . . . and I’m the only person who really knows about anything she feels” (male confidant). In contrast, people with no confidant did not feel that they had this type of emotional support: “And it does make you feel left out, lonely, isolated, all those sorts of things because I don’t have a partner” (female person with MS with no confidant).

Furthermore, the findings suggested that those who did not have a confidant appeared to have had problems in the past with relationships unrelated to MS that had affected their willingness to trust others in an intimate way. Some had been divorced, and some had had a series of unsuccessful experiences. Others felt that having a confidant would force them to admit that they needed help with their MS: “. . . but I’m still not gonna admit it to myself that I need a confidant because to me a confidant for MS means I’m worried about it, and I’m

not, it’s just an illness” (female person with MS with no confidant).

Facing Reality

The person with MS and the confidant faced the reality of living with MS together. The impacts were multiple and related to dealing with the effects of bureaucracy, relationships with health-care professionals, and relationships with family members and intimate partners.

Bureaucracy. The benefit system involves completing forms that increase the feelings of being defined by the disease and inevitably require a focus on the negative. The process was considered stressful by many participants. For example, one confidant described dealing with the reality of managing care for her son: “You’ve got to nag all the time—I’ll phone the nurse all the time and I’ll nag her and she in turn nags other people. I mean, he hasn’t had his physio yet. . . . The occupational therapist was very good at gizmos. . . . But it’s the support that’s wanting. . . .” (female confidant).

Relationships with Professionals. The people with MS talked about their frustrations in having to repeat their story with each clinician they met. When asked by the researcher what they would like her to mention to the professionals when she ran their focus groups, the following comments were made with a tone of irritation: “Perhaps to know they’ve read your notes! That might help” (female person with MS). “And not to ask you dumb questions like when were you diagnosed?—It’s there in black and white, look!” (female person with MS).

Intimacy. One interviewee explained how the physical symptoms of MS had affected her ability to enjoy an intimate relationship with her husband: “It’s a chastity belt I never wanted” (female person with MS). When the focus group members were asked about whether they could discuss these issues with professionals involved in their care, they explained that the professionals seemed uncomfortable when intimate subjects were brought to their attention: “It’s a very good way of ending the conversation before it’s even got started!” (female person with MS).

The confidant relationship allowed people with MS to reduce some of the stresses related to facing the reality of the disease: “That’s basically what [the person with MS] and my life have been together, every time something rears up, we deal with it and that’s it. We might stamp our feet and have a bit of a cry, whatever, but we get on and deal with it” (female confidant). In con-

trast, those with no confidant were faced with frequent reminders of the everyday difficulties of living with MS by themselves: “Well every time you come to these groups or in hospital—I especially notice in hospital—and they just assume that your partner will do this, or your partner will do that, or your partner will bring you in a newspaper, or your partner will pick you up from the hospital. Well what happens when you don’t have a partner—what do you do?” (male person with MS with no confidant).

Discussion

To our knowledge, this is the first study of confidant relationships in MS. The findings demonstrated that all participants with MS, whether or not they identified themselves as having a confidant, had very clear views on the definition of this role and how such a relationship would be of benefit to them. Those without a confidant saw part of their current struggle as finding someone who might offer them emotional comfort. For the confidants, the value of having been chosen for the role and the reciprocity experienced because of it seemed to be sufficient reward for the effort involved in helping the person with MS to maintain a sense of normality. The confidant relationship appeared to offer a shield from outside pressures, from the demands of clinical care and treatment to the pressures from a society that does not always respond positively to people with an impairment.

We used a phenomenological method because of our interest in understanding the experience and impact of “living-in-the-world” with MS. We specifically looked for evidence of this during analysis and recorded those moments when it appeared that the person with MS or the confidant was describing how it felt either to have MS or to share a psychosocial bond. The data suggest that throughout their lives, people with MS feel normal and at ease until their bodies, or the outside world, “remind” them of their condition. This “reminding” can happen when a symptom of MS such as reduced mobility or fatigue reduces their ability to enjoy life or participate fully in it—for example, when they have difficulty accessing public buildings because of insufficient facilities for the impaired. The impact of these negative consequences is eased by the type of informal support the confidant provides, which appears to center around promoting and maintaining the feeling of being and being seen to be normal—as one person with MS defined it, “humanity without the fuss.”

Some have suggested that normality, or feeling normal, is being able to achieve emotional balance and maintain a positive self-image.¹⁷ Yet others point out that the need to return to feeling normal following a diagnosis of MS is “naïve optimism,” an avoidance of reality or denial.¹⁸ In our study people with MS recognized that they had MS and were able to discuss its impact on their lives, which suggests that they were not in denial. However, they felt a strong sense of wanting to be, and to be seen to be, normal. In this context, people with MS saw the confidant as central to their efforts to feel normal and an important component of their psychosocial care. The unspoken understanding between them of the need to maintain a sense of normality was the basis for this positive supportive collusion. Thus, although *collusion* usually carries negative overtones, it was seen here as a positive relationship between the two people.

These findings have direct relevance to the design of health-care and social programs for people with MS and potentially for people with other lifelong conditions. The results suggest that the aim of care programs should be refocused on enabling people with MS to feel normal and be a valued part of society. As Shakespeare and Watson¹⁹ wrote, “a mature society supports everyone on the basis, not of the work they have done, but of the needs they have.” Government policies²⁰ and research in this area recommend an increasing emphasis on recognizing and valuing the expertise of patients and carers within a culture that places growing value on psychosocial support. Our research identifies some of the factors that may hinder the integration of psychosocial support into health-care and social services, such as inadequate resources, training, and time available to work with individuals with MS. The challenge for care providers is to encourage debate on sensitive topics such as intimacy and then to establish systems and training programs for those who are able and willing to address these issues with patients.

Strengths and Limitations of the Study

Use of the phenomenological approach was valuable in helping us to understand the “position-in-the-world” of people with MS and how others’ perceptions of them affect how they, together with their confidants, manage their condition. The individual’s context (eg, the disease status at the time of interview) was taken into consideration throughout the thematic analysis. The results were developed and augmented by focus groups with participants. The journal of the primary researcher (JG)

provided information on and insight into her immediate responses following the interview and her reflections on the interview at the time of analysis. The journal entries were used as a mechanism to discuss with her academic supervisors possible bias introduced into the analysis by her professional experience as a nurse, thus enhancing the rigor of the research process.

The study participants were drawn from one region in England; therefore, care must be taken in transferring the findings to other settings. However, the successful recruitment of a wide range of people, including those without an identified confidant, enhances confidence that the themes that emerged are likely to be applicable to people with MS across the different forms and natural history of the disease.

Implications for Clinical Practice

The increasing demands on health-care professionals' time appear to restrict their ability to offer prolonged psychosocial support to people with long-term conditions such as MS. Indeed, in recent years some commentators have observed that the psychosocial support traditionally seen as being integral to the nurse's role has become sidelined by the provision of physical nursing care.²¹ Nurses have been described as "often standing at the centre of the web of health care holding things together."²² We suggest that nurses and other health-care and social-services professionals use their knowledge and abilities to recognize how distressing negative perceptions of others can be for people with MS. Our findings suggest that these professionals should recognize the important role that confidants play in providing psychosocial support, and consider ways in which professionals can further enhance the confidants' involvement in care.

PracticePoints

- For many people with MS, the primary source of emotional support is a relationship with a confidant, who may or may not be the person's spouse.
- Raising the profile of confidants to enable them to participate in discussions of patient care may be beneficial to MS treatment planning.
- Increased emphasis should be given to the confidant relationship as an important element of psychosocial care for people with MS.

Emotional intelligence, which has been defined as "the effective regulation of emotion in self and others,"²³ is a fundamental quality of good nursing and holistic care. This characteristic has been related to the skills required by nurses in "interpreting how patients [people] feel, ascertaining their motives and concerns and demonstrating empathy and care."²⁴ Recognition of the importance of emotional intelligence acknowledges the new role for nurses and other health-care and social-services professionals in removing previous barriers and encouraging intimacy. It may be possible for health-care and social-services professionals—and perhaps nurses in particular—to adopt the "transient confidant" role when caring for people with MS, providing needed intimacy at times of acute distress. Maintaining a balance between unspoken understanding and supportive collusion may help their patients maintain their "sense of normality" during exacerbations of MS.

More generally, there is a need to work with people with MS on issues that are important to them, rather than those deemed important by professionals. This requires understanding the individual's view of normality and the ways in which he or she can feel in control and best manage the everyday experience of living with the disease. Involving the confidant in the caregiving role offers advantages in care planning but also raises issues related to confidentiality that need to be considered by the spouse, the confidant, and the person with MS.

For health-care providers who feel able to discuss issues related to intimacy with their patients, training and information must be made available in a form that can be adapted to suit the needs of individuals with MS and their partners. Increased collaboration with local agencies that provide emotional support is important to facilitate a more holistic approach to the care of people with long-term conditions such as MS.

Future Research

This study has shown how a particular kind of psychosocial support, that of a confidant relationship, can be of value in both the adjustment to MS and the long-term experience of living with the condition. Research is needed on the possible effects of confidant relationships on health outcomes and how these outcomes may be affected by duration and trajectory of disease. Further research on how best to deliver local psychosocial support to people with long-term conditions at different points in the disease trajectory may also be of

benefit. The present study did not explore the ways in which the confidant relationship might be affected at the end of life, particularly when the confidant is not the patient's spouse. For example, increasing understanding of the interrelationships of family and friends at critical times such as these in the patient's journey would be valuable. □

Acknowledgments: We would like to thank the members of the steering group for their advice and support and all the people with MS and their confidants who agreed to take part in this study.

Financial Disclosures: The authors have no conflicts of interest to disclose.

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