

Husbands and Wives Living with Multiple Sclerosis

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Abstract: Multiple sclerosis (MS) frequently is diagnosed in young adults. Coping with symptoms of MS is challenging not only for the person with the disease, but also for his or her spouse. The well spouse often assumes the caregiving role. The purpose of this qualitative research was to investigate the experiences of persons whose spouses have MS. Twelve people participated in a 2-hour focus group: 8 men and 4 women. The husbands were, on average, 50 years old, and the wives averaged 55 years old. The length of time since diagnosis ranged from 2 to 11 years for the husbands and from 3 to 13 years for the wives. The focus group discussions were audiotaped and transcribed verbatim. Participants talked freely. Four major themes emerged: caregiver roles, need for information, relationship changes, and barriers. Men attempted to protect their wives' energy, intervening for them. Wives encouraged independence in their husbands. Spouses need information about MS, complementary interventions, and support. They want increased public awareness of invisible symptoms and awareness in the workplace of continuing capabilities of persons with MS. Role reversals were challenging for the women who felt that "MS is the third person in a marriage." Spouses need help to maintain appropriate boundaries. Limitations of the study include the small, economically homogeneous sample and the single encounter with the subjects. A longitudinal intervention study is needed.

People expect to become caregivers for babies, children, and elderly parents. They do not, however, expect to become caregivers for a chronically ill spouse at a time when they are focusing on developing a career, providing for their family, and caring for their children. Thus, spousal caregivers of people with multiple sclerosis (MS) face unique challenges and demands. With its physical, social, and psychosocial effects, this disease permeates all aspects of family life (Artinian, 2001; Holland, 2003; Weihs, Fisher, & Baird, 2002).

MS is unpredictable and symptoms vary, even among those with the same type of MS. The psychological and

emotional aspects of MS and the uncertainty regarding symptoms and prognosis are challenging to patients and family members (Coleman, Rath, & Carey, 2001). MS demands flexibility. During periods of exacerbation, the family must quickly mobilize resources and move into crisis mode (Patterson & Garwick, 1994). Invisible symptoms of MS (e.g., visual and sensory losses, fatigue) can confuse family caregivers. For example, debilitating fatigue, which is characterized by a lack of energy that is worse in the afternoon and evening, can occur suddenly (Kaplan, 1999) and may be hard for a spouse to understand and appreciate.

MS does not alter normal family developmental stages but rather adds new demands and challenges. For example, child care does not stop when one parent has an exacerbation; thus, the well parent often adds child care responsibilities to his or her other chores. Caregiving partners experience fear of an uncertain future, social disruption, financial difficulties, and isolation (Rees, O'Boyle, & MacDonagh, 2001).

Spouses are expected to provide support while needing support. They, too, experience numerous losses: role and relationship changes, and possible career and financial changes if their wives or husbands had been employed. These stressors can lead to ineffective self-care for the wife or husband; the reciprocal effects of illness can create enduring strain for partners (Kuyper & Wester, 1998; Pakenham, 2001). Indeed, the effects of MS ripple through the family, with each person's reaction affecting other family members.

Patients frequently have fluctuating symptoms. Spouses attempt to make sense of the nebulous symptoms while trying to be supportive and continuing their normal routines. The time from first awareness of symptoms to diagnosis can be long, frustrating, and confusing. The waiting and wondering, with unrewarding and untherapeutic encounters with healthcare professionals, can lead to feelings of powerlessness and loss of a sense of control for people with MS and their spouses (Courts, Buchanan, & Werstlein, 2004).

This research investigated the lived experience of spouses of people with MS. This investigation was a first step toward developing more effective interventions for these caregivers.

Method

Design

Focus group interviews have been used to assess the experiences and opinions of husbands and wives of people with MS (Polit, Beck, & Hungler, 2001) with a goal of

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obtaining “an authentic insight into the participant’s experiences” (Burns & Grove, 1999, p. 359). The data from the current study were collected by two doctorally prepared nurse counselors and a senior nursing student research assistant. The university’s institutional review board approved the research. Each participant signed a consent form agreeing to participate in the audiotaped focus group.

Procedure

The staff of the Multiple Sclerosis Society (MSS) chapter in a southern state identified a list of potential participants, and a volunteer or staff member called each for permission to release his or her name to the investigators. The research assistant called potential participants, explained the research process, and invited him or her to participate. A snowballing technique was then used by which participants provided additional names. Each participant received \$20 for completing the interview.

At each focus group, participants were given an explanation of the focus group process and research purpose and an opportunity to ask questions. Confidentiality issues included use of first names only and instruction that all information remain within the group. Each person was asked to give date of birth, spouse’s type of MS, and length of time since diagnosis. Each participant was then given an uninterrupted time to share experiences. The two groups of 8 men and 4 women met for 90 minutes and 2 hours, respectively.

Data Analysis

The audiotapes were transcribed verbatim. Each of the investigators worked independently, read and reread the transcriptions, took notes, and identified categories. Passages of interest were discussed, retyped, reread independently, and discussed again. Similar passages were grouped under one category or heading, and those not found compelling were removed. Emerging themes were identified. Each investigator then selected a theme, reread the transcription, and retyped verbatim comments related to that theme. The themes were discussed until consensus was reached.

Results

Sample

Eleven men and 10 women were contacted. Eight husbands and 4 wives participated in the two groups, for a response rate of 73% for the men and 40% for the women. Reasons given for nonparticipation included inconvenient meeting date, the person was no longer married, and lack of interest. All respondents were Caucasian. The sample was representative of the MS population in terms of gender. The ages of the husbands ranged from 31 to 67 years ($x = 49.5$) and the ages of wives were 50–65 years ($x = 55$). The men stated that the time since diagnosis ranged from 2 to 11 years ($x = 5.5$). They said,

however, that they believed their wives had had the disease for a longer period of time. The women stated that the time since diagnosis ranged from 8 to 10 years ($x = 9$).

Four major themes were identified. The first theme described the spouses’ role as caregivers, with men as protectors and women as advocates. The second theme revolved around the need for resources, such as information about MS, complementary treatments, and support services. The third theme described relationship changes, such as role changes and strengths. The last theme, barriers, identified both human and environmental barriers.

Caregiver Roles

Both groups discussed assuming the caregiver role, which was focused on supporting their spouse, limiting the negative consequences of MS, and preserving their quality of life by promoting spousal independence and sense of self-worth. Both groups believed that the caregiver role was congruent for women and not for men. One man stated, “Men as caregivers . . . we are really not used to that.” The wives agreed, saying, “Women are usually the nurturers, the carers. . . . I don’t know what my husband would have done. . . he probably would have left me . . . ’cause he wouldn’t know how to cope with it.”

There were gender differences. The roles of the men were predominately that of “protector” and those of women were “advocate.”

The men’s protector roles included attempting to protect wives’ energy by confronting church and family members, halting or changing activities perceived to overburden or fatigue their wives, and advocating for activities and employment that would ensure their wives’ feelings of self-worth.

The men discussed in detail their instrumental support of their wives. They swapped information on the best ways to give injections without bruising, types of syringes used, and the use of ice to ease the administration of the injection. They were involved in taking over household chores, accompanying their wives to physicians’ appointments, and providing physical care for their wives, when possible.

Men saw themselves as protectors of their wives’ environment and activities. They paid special attention to ensuring their wives’ sense of self-worth and protecting them from excessive energy expenditure. Men, as protectors, took an active role in controlling the environment. One said:

I have to go and put the law down at our church, because they ask her to do things because they know she was always available when they had some job nobody else would touch She had too much on her!

One focus group participant said he protected his wife’s energy by intervening with their active 5-year-old son: “I have to sit down with him and work with him

and tell him 'Mommy's not feeling good' and whatever." Another husband was sensitive to the timing of exacerbations. He noted that his wife had three exacerbations at Christmas, explaining them by saying Christmas was "a big deal" with lots of family and stress. He said he told his wife, "let's don't do this quite so strong. . . start buying the presents in September and let family know that this is causing stress."

Other examples of how the men protected their wives were revealed in statements such as, "She keeps going until she is about to drop, and I keep pulling her back saying, 'slow down.'" And, "I have a way of saying you need to go to bed, and it's kind of like a little kid . . . go to bed now!" Another, "She still wanted to play golf, and I said, 'You'll be laid up for 3 or 4 days. Don't do that.'" One man confronted his wife's employer, insisting his wife was able to continue working and demanding fair treatment in the workplace. The husband's attitude was, "Who cares who we piss off? We need to let them know that my wife is still an able and working person first." The husbands looked for other ways to increase their wives' sense of self-worth, such as encouraging them to participate in volunteer activities.

Two men mentioned that their wives thought they might leave the marriage. One explained that his wife thought, "So he's going to leave me," but she did not talk about this for a year. Another husband commented, "It was in everything that she read; the spouse left within the first 2 years." After the fear had been voiced, the husbands were able to reassure their wives. The men discussed their issues and support in a cognitive and concrete manner. "Learning acceptance is bad. It's hard," but after a period of time, it was accomplished.

Wives intervened in very different, but equally strong, ways. Wives described their caregiving roles as advocates, with a focus on keeping their husbands involved, functioning, and independent by not doing things for them that they could do themselves and encouraging them to participate in more activities. One wife commented, "Sometimes [I'm] pushing him to do things that he wouldn't ordinarily do." She insisted, "I told him he was going on the trip with us, and that was the way it was going to be."

The wives described interventions they used to keep their husbands independent. One wife said "I got him this black lab [I] think has been really good for him. He can get out [with the dog]. . . . [It's] really important for him to be able to be independent." They did not routinely go with their spouses for medical appointments because their husbands could do that alone.

Wives became advocates for health care. During the diagnosis period and several drug trials, one woman said, "MS was never brought up until, actually, I finally put my foot down . . . [and asked] can we please have an MRI?"

The wives also were advocates for mental health treatment and quality-of-life concerns. One wife, seeking help

for her husband's depression after the MS diagnosis, described their experience with a counselor as follows:

[W]hat we got wasn't primarily about MS or dealing with disease-induced depression, which is different from clinical depression, which is different from grief depression. We got a talk and an offer of more pills . . . so I think . . . what he would like the best for both of us, is just some genuine support. . . because taking the pills. . . isn't the only answer.

Another wife, who had previous experience with psychotherapy, sought help for herself to deal with her husband's MS. Her actions motivated her husband to join a support group, which he found helpful; he eventually sought counseling for himself.

Even though men were protective of their wives' energy and women pushed their husbands to stay independent, both groups acknowledged being overprotective at times. One man said, "Sometimes I am too doting, you know, or too aware of [her] barriers." A wife explained, "I get overprotective; my problem [is] being overprotective. [I'm] trying to help him out in ways that he really doesn't want." Another said, "[I] found myself being hypervigilant . . . with his situation."

Need for Resources

The need for resources was eloquently expressed by one wife:

MS is a whole life situation . . . and there is so much that isn't addressed. . . . Resources, I would have really appreciated it. . . . Here is the emotional thing, we need some help. . . . We didn't get enough information to make empowering choices . . . dealing with quality of life things.

Resources needed included information about MS and the availability and use of complementary therapies, as well as support for themselves and their spouses. "It is difficult to find a reliable source of information," said one study participant.

On receiving the diagnosis, one man said, "I went to the MS Society immediately as soon as I hung up the phone . . . and got everything I could find to become more familiar with the disease and symptoms and what you do." Another said, "[B]ut I got on the Internet and kind of questioned the MS Society." Another husband also said, "As soon as she was diagnosed, [I went] on the Internet, and we got everything we could . . . tons of stuff available." One focus group participant said that the physician "also told us that Internet-derived information was not reliable information." Most of the men discussed reading, looking for resources, and trying to learn as much as possible about the disease.

Participants said of the resources available from the MSS, "There are brochures and that is the extent of it."

One woman noted the following:

The brochures don't even have 'for information on this, call here or go there,' just general information like you would find at the doctor's office on PMS. It gives you just a glimmer of information and not much on choices.

Daily coping was an issue. One spouse said, "Dealing with those daily quality-of-life things, you are talking about the pain. . . . If there was a *Reader's Digest* kind of thing that we could lay our hand on initially. . . . [it would be] very helpful for us." The groups wanted to know more about MS; they said they needed information about treatments and medications.

Husbands expressed the need for friends and family to know more about MS, too. One husband said "The biggest thing . . . or problem is the public view of MS . . . for my family, her family, and friends to know exactly what this is." Another husband stated, "The greatest problem that she's had . . . is outsiders understanding this, and even her own parents don't really comprehend how difficult it is for her." They experience resentment from friends. According to one focus group participant, a friend said "We're always coming to your house. You don't ever come to ours'."

Lacking information and feeling insecure about options, many participants searched for other therapies that could complement or even replace the medical regimen. One husband commented, "We are also trying to find out other ways . . . or other supplements and some other treatments and what exercises to use and see what works for her." Another husband said, "My wife and his wife are swapping mixes on their vitamins right now. They're going through a kind of study on what they're going to take" and ordering "\$800 worth of stuff" from a nutritional healing book.

The husbands shared complementary interventions that had worked for their spouses. One husband said "I do recommend water aerobics . . . her mobility has improved probably tenfold and she doesn't have as many [falls]." Other exercises used included treadmill walking and stretching. One wife drank "ground-up flaxseed oil and soy milk in the morning. She's got it down to a routine." Other methods used included aromatherapy, muscadine extract, magnesium citrate, bee stings, and so forth. One man said he talked to the physician before using herbs and vitamins. A chiropractor suggested some herbs for one patient, and "the doctor said 'if this works, I want to know because I will do a clinical trial on you'." There was a lengthy discussion of this topic.

Overall, both groups wanted to maintain their current lifestyles and needed "something more holistic. Quality of life is what it's about for us." The men discussed the need for support in matter-of-fact ways. They discussed going to support groups with their wives, saying "you

can sit around and talk about it and learn how other people are dealing with it." Another husband discussed e-mail counseling but cautioned, "When you get that anonymity factor in, people feel a lot less inhibited." Some husbands looked for ways to increase their wives' activity because they didn't think their spouses were physically active enough, but all were involved with ways to increase their wives' "sense of worth."

The women's need for support was overwhelming, and they acknowledged their emotional needs with poignant descriptions. They said that MS was the "third person" in the marriage and that they, too, had the disease. They focused on the need to have someone listen, ask about and respond to their needs, and help them cope. They were quite open in identifying their emotional reactions and needs for support. One explained:

There are times I would like to roll around on the floor and scream and tear my hair out and say 'I'm all better now' and go home. You know! With women [who] understand where I am coming from.

The need for someone to reach out to them was eloquently described: "Just once, somebody out there someplace come and put their arm around me and say 'You are going to be fine. Here, let's take care of the [problem].'"

The women complained about the lack of interest from family and friends:

They say . . . 'How are you?' and you say 'fine,' and they don't even hear past the 'fine'; they don't really want to know that he had an exacerbation . . . and he had an accident and couldn't get to the bathroom in time.

Another participant, more reserved and private, explained, "Some people are just not comfortable talking . . . especially if it gets into the more intimate aspects of their life. E-mail counseling . . . where a person can submit a question . . . get that anonymity factor [would be helpful]." Participants' suggestions included "peer counseling from spouses [who have been] involved in it for quite some time;" "some genuine support around that [illness];" and "the names of other MS groups that your husbands go to." It was clear that spouses needed support for themselves, and they wanted support for their wives and husbands. They often felt overwhelmed, ignored, and neglected.

Relationship Changes

Relationship changes were described as both positive and negative. The spouses noted how MS had changed their roles and sometimes led to role reversal. Men discussed their new role as caregiver. Comments included: "It was tough. . . but within 3 years, we as a couple had adapted," "My marriage is stronger than it has ever

been,” “I’ve become a better caregiver, no doubt about it,” “I feel needed. I knew I was needed,” and “You are thrown into a role, [you] learn it; it’s a very healthy thing.” The husbands consistently discussed the issues using the word “we.”

One wife described becoming the main breadwinner as follows: “But that is the hardest thing . . . the role reversal, ‘cause he is at home.” She had been a homemaker while her children were growing up, establishing close relationships with them. Her husband, because he was at home and available, was now receiving and writing e-mails to one of their children who was away at college. She explained how her husband “got to know their daughter better. That has been real positive” and both said that “he is the only dad who e-mails almost every day . . . and I say ‘wait a minute, this is from me, too!’” She appreciated that they were close but experienced loss because she and her daughter “were so close and now they are closer, so that is a positive thing.” This woman’s sense of loss was evident in her facial expression and tone of voice. Another woman related her role reversal to having to do all of the driving, saying, “That is a different thing, always being the one.”

One woman explained:

We have been married 31 years. . . and we hardly ever had an argument. And he never lost his temper, and in the past 5 years he’s blown up and we’ve had shouting matches and I would stop and say, “Calm down, why are you so upset?” . . . The physical things are not as bad as the mental things.

Many of the outcomes described by participants had to do with losses and decisions. One wife explained that she needed some “sincere and honest conversation” about remaining in the marriage. She said:

To stay! You know, and I think that all of us at some level or another have to work through that process. This may sound really terribly selfish but I didn’t sign on for this. And facing all these things . . . as much as I love him . . . Number one, can I do that, and number two, what is it going to cost. . . . [S]ome sincere conversation around those kind of [issues] would have been really helpful for me, I think.

Her honest and sincere sharing of her true feelings set the stage for additional comments. One woman stated, “I feel so sorry for him, and I feel sorry for me, too! I have the disease too, it’s not just one person.” The wives expressed both a desire and a need for someone to allow them to share the dark side of their feelings, ask about them and listen to their answers, and to whom they could be honest about the difficulties they are experiencing. One woman who stated that this was

her first opportunity to be heard had a litany of losses. She began by noting how difficult it had been, and said, “[My husband] has a lot of sexual dysfunction. Part of it is the drugs, . . . [I] don’t know if I can do this [stay married]. Can I do it, and do what I want to?” These are hard decisions. Another wife said, “He is always afraid that I am going to leave him. He says, ‘I’m afraid you are going to dump me someplace [nursing home] and leave me.’”

The wives described how loss of employment was difficult for their husbands: “He went out on disability and that was a real blow to him . . . emotionally;” “[MS] relieved him of his occupation and everything, and his depression was pretty dark, pretty deep, and pretty extensive. He didn’t drive for a year.” All of the women mentioned loss of employment, but most of the group denied that they had financial problems, stating they had good insurance.

MS caused relationship changes with significant disagreements and arguments in marriages that had been harmonious and calm before the diagnosis of MS. One wife reported,

[My husband said], “Why are you going [to psychotherapy]? I’m the one with the disease.” And I said, “Well, guess what? It affects all of us!” It’s like I told him, it’s like three people in a marriage, and MS is the other person.

The spouses sometimes made comments in the heat of the moment, and the participants reported them honestly. For example, one spouse said, “I hate myself for saying it, but I said, ‘It is easier to be you than to live with you! It is a good thing that it isn’t me that had MS, ‘cause you wouldn’t put up with this kind of attitude.’” Stresses of living with MS were challenging and often hard to accept.

In spite of all the adjustments and role changes, the participants identified areas of growth and strength. One woman said:

In a lot of ways I think it has brought us closer. . . . On a lot of levels he gives to me in ways that I don’t think he would if he wasn’t so aware that I was constantly vigilant with this situation.

Barriers

The invisible symptoms of their spouses often caused problems, and sometimes it seemed that these were problems they should not have encountered. The fourth theme, therefore, was barriers—both human and environmental. Barriers were discussed more by the men. Only one woman complained of lack of wheelchair accessibility.

Human barriers came from other people who showed a lack of understanding of MS. One husband reported, “[We need] public awareness . . .” Human barriers also were encountered in the healthcare arena: “It is hard to

get through [office personnel] to [the physicians];” “When you call [the physicians’ office] you don’t get a human being. You leave a message;” “It takes us 2 to 3 weeks to get an appointment;” “Sometimes [the nurses/receptionists] seem to think they are there to make diagnostic decisions.” These issues caused a great deal of stress for spouses. That some symptoms of MS are invisible led to remarks such as, “When [friends] see her out they say, ‘Well, you don’t look like you’re sick,’” expressed in tones of anger and disgust.

The men expressed anger at the difficulties they had when parking in the spaces reserved for people with disabilities because of the snide remarks made by strangers who thought they looked healthy. “When . . . [they don’t] see any physical ailments when you are getting out of your vehicle, they can be extremely rude. That’s the biggest problem we have.”

One man described an especially unpleasant episode involving his wife. He said, “She was falling and had bruises.” Her coworkers “thought I was beating the crap out of her. . . [and] had a police officer there” who arrested him. His hurt, anger, embarrassment, and resentment were obvious. He complained that no one investigated or asked either him or his wife about the bruises. It was incredibly upsetting to be suspected of physically abusing his wife.

The men complained about the accessibility of aisles in department stores to their wheelchair-bound wives. “The ADA [Americans with Disabilities Act] rules read clearly either 36 to 48 [inches] on aisle ways. . . and it’s certainly not anywhere near that.” Another explained how he dealt with his problem: “My wife’s coming through on her scooter [and I] . . . just move the display. I mean it’s terrible what they are doing and what they are getting away with.” The spouses could identify areas that were and were not handicap-accessible, discussed ADA rules, and mentioned ways to enforce the rules. They believed that “the public doesn’t understand what we are having to go through.”

Discussion

As caregivers, the study husbands and wives were concerned with limiting the negative effects of MS and preserving and improving their spouses’ and their own quality of life. There were gender differences in how the study participants experienced their caregiving roles and how they expressed their feelings. The husbands mainly described their experiences objectively, but felt anger about human and environmental barriers. The wives related their experiences with much more feeling and described their pain. The men acted as protectors of their wives’ time, energy, and employment opportunities and were angry at those who did not understand the effects of MS on its sufferers. These husbands demonstrated their support by assuming more responsibility for household

management, participating in giving injections, and going with their spouses to see their physicians. The women described with great feeling major lifestyle changes and role reversals. They became advocates to help their husbands maintain independence and existing roles.

The lifestyle of the caregiving spouse of a person with MS changes, often resulting in a poorer quality of life (Gregory, Disler, & Firth, 1996). Some husbands and wives described experiencing stronger marriages and relationships following the MS diagnosis and indicated that they worked to make these results happen. Although men and women process their experiences in different ways (Navaie-Waliser, Spriggs, & Feldman, 2002), participants in the current study all experienced a great deal of suffering in silence.

The people with MS were fearful that their spouse would leave them or put them in a nursing home, but they did not express this fear for a long time. The wives longed for a safe place to be heard, so they welcomed the focus group. They sought support and psychosocial help but were given medication for the depression. There is a tendency to label the suffering of patients and families as depression instead of accepting it as a legitimate and normal response to a life-changing condition (Frank, 1998). These focus group participants wanted support, not medication.

Although husbands talked objectively or with anger, wives frequently shared their pain, identifying their emotional needs in strong ways. They described the effects of their husbands’ MS on them, the process of deciding whether to stay in the marriage or leave, and the other hard decisions they had to make. They talked about encouraging their husbands’ independence and maintenance of his functional ability, perhaps because they feared their husbands’ slip into dependence. They expressed a strong need for someone to listen without judging them, care that life is difficult, and ask how they are doing.

Gender differences were important. While other researchers have noted that many spouses fear being disloyal and therefore, are reluctant to express their concerns (Rees et al., 2001), these men and women saw themselves as experiencing new roles that demanded adjustment; both groups reported experiencing pain and frustration, but also growth. When a spouse develops a serious illness, there is a direct effect on his or her partner; each is concerned not only about his or her spouse but also about his or her own life (Kuyper & Wester, 1998). This effect was especially evident among the wives, who would have liked to relinquish the role reversal in their marriage.

All of the participants identified the desire and need for information and support, which corresponds with other findings (Gulick, 1994). It is unfortunate that this issue still has not been resolved in the healthcare setting.

The participants who gleaned information from the Internet were aware that this information could be inaccurate and were distressed by this awareness. The lack of information may have been the stimulus for these couples to experiment with complementary interventions. This experimentation can have serious health consequences because the combination of some of the therapies can reduce the benefit of some prescription medications and cause unpleasant side effects (Courts et al., 2004).

MS has a psychosocial effect (Benbow & Koopman, 2003; Courts et al., 2004; Hakim et al., 2000; Mohr et al., 1999). The wives were eloquent in expressing their difficulties, describing MS as the "third person" in their marriage, as affecting the whole family, and as stimulating anger and thoughts of leaving the marriage. The wives had difficulty assuming some of the roles thrust upon them; hence, they encouraged their husbands to be independent and pushed them to be more active. Friends and family were a source of stress because they did not understand MS. Friends tend to disappear because they feel too threatened by the suffering and are unable to face the tensions and demands of the illness (Frank, 1998).

Limitations and Implications

This study is limited by the small convenience sample and its single data-gathering period. The data, nevertheless, have a number of implications for nursing. First, the caregiver role was so important to these husbands and wives. The data suggest adjustment is not contingent upon length of diagnosis, so assessment needs to be ongoing. Spouses need to be assessed individually and privately, as well as with their partner. Patients and spouses need an opportunity to deal with personal issues, such as fear of divorce or difficulty deciding to stay in the marriage, in a safe environment that can reduce loneliness and facilitate adjustment. If referral to a mental health professional is indicated, nurses need to be sure that the therapist understands the issues associated with MS.

Because male caregivers tend to be protectors, nurses can be helpful in working with the couple to identify ways this role can be integrated successfully into the care plan, that is, determining when the protector role is needed and when it may become troublesome. Spouses and patients may need help to maintain personal, appropriate boundaries to avoid overprotectiveness and to preserve the independence of both the patient and the partner. Stressful lifestyles can be changed with discussion and planning, and patients can learn to accept limitations when supported by their spouses.

In addition, although the men were more cognitive than affective in describing their experiences, both husbands and wives indicated difficulties related to the diagnosis. Relationship changes, lifestyle changes, losses,

and the need for information were major concerns. Information should be freely available at the time of diagnosis and throughout the illness. Resources need to be available at the physician's office, referrals made to the MSS, and appropriate Web sites identified. The opportunity for couples to ask questions and receive honest answers could help alleviate unnecessary suffering.

Barriers included difficulties in gaining access to physicians, the ignorance of the public about "invisible symptoms," and retail stores with aisles that are too narrow for a wheelchair. Physicians' nurses should return calls in a timely manner, refrain from speaking for the physician, answer questions, communicate with the physician, and then call the patient or spouse back to follow up. Nurses could offer MS education programs for friends and the general public. News releases about the "invisible symptoms" could increase public understanding of the use of parking spaces for people with disabilities and the problems of shopping from a wheelchair.

The spouses in the study expressed a need for a holistic approach to the diagnosis and alternative or complementary therapies. Music therapy, for example, can produce relaxation and change one's emotions (Guzzetta, 2005). Nurses can use mental imagery to alter expected outcomes (Schaub & Dossey, 2005). These alternative therapies also give spouses "something to do" and enable them to avoid relying solely on healthcare providers, increasing the sense of control.

Exercise programs also can be beneficial, increasing control while improving physical health (Newland, 1999). Healthy lifestyles for both patient and partner improve their quality of life. Because alternative interventions can cause side effects (Courts et al., 2004), nurses should carefully assess responses to alternative interventions. Nurses are in a unique position to initiate discussions, explore perceptions, and provide information, support, and guidance.

Finally, patients and their spouses should have access to support groups. Nurses should determine whether patients and their spouses are using them and if the groups are beneficial. If they are unwilling to go to MSS groups, they could be encouraged and supported to arrange their own groups. Even Internet support groups could be beneficial. Indeed, friends and family often are available, and nurses could volunteer to meet with them during an initial meeting. The opportunity to express feelings and receive validation is critical so that partners can then be supporters for their spouses.

Further Research

With a diagnosis of MS, both patients and their partners are affected. A longitudinal, experimental intervention study for patients and their partners is needed to help them deal with the challenges of MS, maintain healthy lifestyles, incorporate appropriate changes, and

maintain a good quality of life. A nurse, coach, or advocate is needed to help couples identify their needs and values and create a plan of action to achieve their goals within the parameters of the disease. Listening to patients and families does take time, but the outcomes of being heard can change the illness experience.

Summary

The spouses of people with MS play a critical role as caregivers, and their needs must be addressed as part of an overall, effective care plan. The data support the critical need to include spouses in managing the illness, learning advocacy skills, and finding ways to manage the illness. Educating the public about “invisible symptoms” and reminding businesses to provide for their wheelchair customers would enhance the lives of this population. These data add to nurses’ knowledge of what it is like to be the spouse of a person with MS.

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