

Focus Groups: The Lived Experience of Participants with Multiple Sclerosis

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Abstract: Multiple sclerosis (MS) is a chronic disease affecting young adults. The presence of the sometimes-invisible symptoms (loss of vision, fatigue, incontinence) and the episodic nature and uncertainty of symptoms can create a constant sense of vigilance or support the use of denial. Indeed, family, friends, and even nursing support may be elusive, leaving one feeling lonely, frightened, and insecure. The purposes of this research were to investigate the lived experiences of people with MS and examine their needs from their perspectives. Two focus groups included 4 men diagnosed with MS from 2 to 15 years and 6 women diagnosed with MS from 1.5 to 15 years. Four themes were identified. The first theme resonated around feelings that "nobody listened." The second theme, symptom devastation, described the overwhelming presence of symptoms and the difficulty they caused. The third theme was "picking and choosing," or making choices to maintain some control. "Fight your own fight" with self-advocacy and taking charge was the final theme. Even though MS continuously caused challenges and changes interfering with goals, participants described creative solutions. They learned to deal with the denial, refocus their priorities, plan their activities, and choose carefully. They described a litany of being unheard, unimportant, and confused, which led to feelings of dejection, desperation, and depression. Their most poignant need was someone to listen and teach since they identified knowledge as power. The data gathered contribute to knowledge and understanding of people living with MS. Findings support nursing interventions that empower and teach self-management techniques.

Multiple sclerosis (MS) is a chronic, often progressive, degenerative, inflammatory, neurological immune disease, characterized by demyelination of axons. MS signs and symptoms early in the illness frequently include sensory loss (numbness), weakness, blurred vision, while in advanced disease cerebellar findings (ataxia, tremor, dysarthria) are more prominent (Schapiro, Scheinberg, Weiner, Wolinsky, & D'Epiro, 1997). The course of MS is unpredictable in terms of signs and symptoms and resulting disability (Somerset, Campbell, Sharp, & Peters, 2001).

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Indeed, the hallmarks of MS are "uncertainty, variability and unpredictability" (Koopman & Schweitzer, 1999, p. 17). MS may be episodic or continuous, transient and mild, or progressive and severe. The presence of the sometimes-invisible symptoms (vision problems, fatigue, pain) plus the uncertainty of exacerbations can create a constant sense of vigilance or support the use of denial. Not only does a diagnosis of MS interrupt one's life, demanding adjustment, adaptations, and new reservoirs of coping strategies, but it is also accompanied by losses, feelings of powerlessness, and stigma (Hilton, 2001).

Patients, along with their informal caregivers, spouses, family, and friends, face continuing challenges, changing treatments, and often frustration. Indeed, family, friends, and even medical support may be elusive, leaving one feeling lonely, frightened, and insecure. Persons diagnosed with MS described the period before diagnosis as a time of trying to make sense of the symptoms, seeking medical help and feeling powerless since "Listening ears and supportive voices were missing" (Koopman & Schweitzer, 1999, p. 20). The diagnosis was described as stimulating feelings "of being emotionally wounded" (p. 20). The diagnosis brought relief for some but additional stressors and problems for others, including fears about interpersonal relationships and concerns about continuing normal work patterns and home responsibilities.

Miller (1997), in an in-depth, 6-month qualitative study of 10 people with relapsing MS, uncovered 12 themes ranging from psychosocial responses to issues about revealing the diagnosis and the social network. Baker (1998) found that during an exacerbation people had difficulty identifying their symptoms as MS and not a virus, and they experienced resurfacing of the grieving process. Further, participants described limitations not only in ability to communicate verbally (difficulty finding words, cognitive impairment) but also in interpreting nonverbal cues due to visual changes (Yorkston, Klasner, & Swanson, 2001).

Given the unpredictable trajectory of MS and its challenges, nurses need to understand the illness from patients' perspectives. This inquiry, therefore, investigated the lived experience of people with MS and examined their needs from their own perspectives.

Method Design

Focus group design was used to investigate the concerns and problems or lived experience of a group of men

and a group of women with MS. Focus groups encourage spontaneous flow of experiences and ideas and permit exploration of content (Price & Everett, 1996). Investigator triangulation was used to reduce bias and increase thematic validation (Pollit, Beck, & Hungler, 2001).

Procedure

The Multiple Sclerosis Society (MSS) in a southern state identified potential participants. A volunteer or staff member at the MSS called to ask permission to release their names. With approval of the university Institutional Review Board, a research assistant called potential participants, explained the study, answered questions, and invited them to participate. Three investigators attended each of the focus groups, which were audiotaped with the participants' full knowledge and written consent. The tapes were transcribed and then destroyed. Each participant received \$20 for participating.

Group boundaries included use of first names only, agreement that all comments would stay within the group, and other assurances of confidentiality. Each participant was asked to introduce himself or herself with first name, date of birth, type of MS, and date of diagnosis. After introductions, each participant was given a period of uninterrupted time to share his or her experiences. In order to obtain spontaneous comments, discussion began with an open-ended statement: Tell us about your experiences with MS (Kidd & Parshall, 2000). The next question was, What could healthcare professionals do to make things better? Each focus group lasted approximately 1 1/2 to 2 hours.

Data Analysis

The focus group audiotapes were transcribed verbatim and analyzed by the investigators in order to identify themes. Each investigator independently identified themes and supporting statements. The three investigators met, discussed the themes, and came to a consensus about theme identification. Supporting statements were again identified under each theme and further refined.

Results

Sample

Ten women were invited to participate, 8 agreed to do so, and 6 attended the focus group. Three men were called and all accepted. An additional man was identified during the calling process, and he agreed to participate for a total of four men. Length of diagnosis ranged from 1.5 years to 15 years (mean = 5.6 years) for the women and from 2 to 15 years (mean = 6.9 years) for the men. The age range for the three women who gave their date of birth was 41 to 53 (mean = 47.3). The men ranged in age from 28 to 59 (mean = 45.7).

The participants shared their thoughts openly and with genuine truthfulness. They described their personal journeys beginning with first symptoms and identified coping strategies as well as concerns. Interestingly,

group members listened carefully to each other's stories, frequently nodding in agreement and occasionally asking a question or making a comment. The men were as vocal as the women; they asked each other questions, made comments on what was said, and suggested ways to manage symptoms and problems.

Four themes were identified. The first theme resonated around their feelings that "nobody's listening." The second theme, symptom devastation, was based on descriptions of MS symptoms that came from nowhere and left them weary, confused but able to endure. The third theme, "pick and choose," demonstrated how they regained some power over their lifestyles with the subthemes of "control" and "denial." They described the need to "fight your own fight," the fourth theme, by becoming a "self advocate" and taking charge of lifestyle changes.

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Nobody's Listening

Nearly all of the participants felt that "nobody was listening" to them when they reported their symptoms to doctors and nurses. Some felt that even those who paid attention to their symptoms were unable to "pull" the symptoms together. One man described how in desperation he diagnosed himself, and the insensitive remark of the physician. He said,

My leg started giving way years before I was diagnosed. I went to the doctor. And he misdiagnosed me...arthritis...went into my eyes... ophthalmologist... [said] don't do anything and it should go away. ... But it got worse...and [I] said I think my eyes are related to my legs and the feeling in my fingers and stuff...He told me that of all the things that could have happened, I'm pretty lucky that it is only MS. I didn't feel lucky at all!

He spoke in a well-modulated tone of voice, but his anger was evident. Flippant, off-the-cuff remarks (such as "it's all in your head," "you're lucky it's just MS") were described in great detail indicating the pain they caused. Participants recited a litany of comments that made them feel unheard, unimportant, and discounted.

One way to discount people is to suggest they are imagining the symptoms or that symptoms are not real. One participant said,

Well, somebody's going to tell you it's in your head. They are going to send you to a psychiatrist, [so] you're not going to complain too much.

Another added,

The doctor who couldn't figure out what was wrong, told me it was in my head, which angered me very much because I was never a hypochondriac.

Comments from professionals indicating that nothing was really wrong with them brought not only anger but also sadness and frustration. One person stated,

...[I] was diagnosed and started to feel better that it wasn't in my head like other people would say....

Some had symptoms for years before they received a definitive diagnosis. Not surprisingly, before being diagnosed with MS, they had received a variety of diagnoses from a brain tumor to transverse myelitis, fibromyalgia, stroke, vertigo, and arthritis. The pain and frustration of being ignored, not taken seriously, and put down were poignantly described by a young man as he reported that he was told "there is nothing wrong with you." The experience of symptoms without being taken seriously, the frequent misdiagnoses, and, finally, the discounting comments led to feelings of dejection, desperation, and depression.

The participants not only talked about how nobody was listening but also described how they needed a listener. One said eloquently,

All we need now and then from the healthcare professional(s) are to be good listeners. We do not need

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people to tell us it is all in our head. And we knew it was all in our muscles.

They described this good listener as "A person that doesn't comment back, or that doesn't look at you like...I've heard that fifteen times already" and "a compassionate, caring person." Even though there were no answers or solutions to their problems, they wanted a professional to stay with them, listen, and hear their concerns; they needed to be taken seriously.

Symptom Devastation

Participants also described how dramatically MS had changed their lives, presenting them with difficulties beyond their imagination. The devastation of the MS symptoms stopped them and they were forced, on an hourly basis, to do "battle" to maintain some normalcy in their lives. The women talked about how MS interfered with what they wanted to do and every man described the effects of MS on employment. One woman said,

You have to plan your days a lot better than you used to. If you don't, you can be stubborn and say I am woman, I can do it all, like we used to do. And you know, ...it slam dunks you...And it does...it puts you in your place.

Another said,

It was slam dunk when I discovered that I had MS, and on a regular basis it is slam dunk.

"Slam dunk," a basketball term used by this population, described the powerful, sudden, and overwhelming symptom onset and lifestyle changes. The ability to adjust to these changes varied, with some describing changes matter-of-factly and others discussing their difficulty.

The men reported different types of devastation but mainly focused on employment. All were concerned about maintaining their work or were disappointed about their inability to do so. They coped in very different ways. A musician changed from playing guitar to teaching others and playing blues on the harmonica. The youngest man, with the shortest time since diagnosis, shared his devastating feelings of defeat when he had to resign from a job that defined his role in his family and community. He said,

I have a very hard time with memory...difficult time focusing...I was shuffled down to a desk. With the memory problems and fatigue and I have a tendency to lose my train of thought. I probably have not gotten over the depression. I am very bitter...I'm not tolerating this very well to be honest with you.

Another man changed the guise of who he was in order to be functional in his work setting. He said,

I had to go to class with sunglasses on and turn all the lights off...I couldn't make it through lecture, I had to sit on a table in front of the class...could not read without my magnifying glass with a light...

The men responded to each other's story, asking questions and/or making suggestions.

Feelings ran high in the group as they described the devastating effects of their illnesses and their pain and anger. Two of the older men reached out to the youngest with suggestions. One man who had been offered disability declined because he was afraid that he would adopt the disabled role and wanted to remain involved. His message was,

And, if you can still work, work. As long as you possibly can. Because you can really latch onto that.

Pick and Choose

The third theme centered on the constancy of making choices. Deliberately "picking and choosing" activities established a sense of control over the disease and supported the denial of progression. Participants with MS lose a great deal of control over their lives; hence it is not surprising that they develop ways to regain it. Taking charge indicates that one is assuming responsibility for one's own life, and denial is a way to control the impact of illness intrusion. "Picking and choosing" involves the

emotional boundaries of the illness so that one can continue living; taking charge and denial are the actions and defense mechanisms used. Participants noted that they had to plan carefully what they wanted to do ("can't do two consecutive days of activity") and said they had to change their lifestyles, including moving to accommodate a wheelchair or other aids.

Participants noted how, in order to take charge, they chose activities, doctors, and attitudes. For example, one described using a wheelchair at the mall to reduce fatigue or using "a wheelchair if I go out for extended periods in unfamiliar places." Taking charge for some participants meant learning how to give themselves injections, finding ways to continue to function on the job or negotiating other aspects of the same work, and planning their day. One said, "I pick and choose the activities and it gives me the control [that] I want and need." One optimistic man said, "If you were reasonably optimistic and you can, hold onto that optimism after the diagnosis." Describing her experience, one woman said, "I [got] two totally different views, opinions, and I chose the opinion that I wanted."

Some chose to maintain control with cognitive restructuring (rephrasing their self-talk) and/or changing their attitude. This was evident in comments such as "I'm not going to let this stop me...I am trying to do things to at least maintain strength and control" and "my belief...is that I have MS. MS doesn't have me." Some participants attributed symptoms such as numbness in the hand to "I slept on it wrong." Even after the diagnosis was made, subjects had difficulty with acceptance as evidenced by such statements as "I do not feel that it is [MS], but I'm sure that it is." As symptoms worsened, they maintained their attitude of control:

When you think of someone in a wheelchair you think that's it, life's over, but it ain't. I don't see myself as a person in a wheelchair.

Respondents reported using denial in very creative ways. One participant who began having symptoms in December did not seek medical attention right away. Her response was:

I didn't really give a whole lot of thought to the fact that there was anything much wrong with me until mid April, even though I'd had those feelings...I had never been sick and I was truly in denial. I told my doctors...an aspirin was going to fix [me]. I will not claim the disease.

Some participants attributed symptoms to other events in their lives such as "just doing too much" or "acting up arthritis," denying a possible exacerbation. One attributed her fatigue and ataxia to a breast biopsy 3 months earlier; it was her gynecologist who asked why she was using a cane to walk.

Even when symptoms worsened, subjects were reluc-

tant to seek medical attention. Instructed to return if symptoms worsened, one admitted that her symptoms did progress but said, "I had things I had to do so I didn't call him." Other comments indicating denial included "it might be MS [but] if you don't say anything, it's not right now." One participant said that by maintaining previ-

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ous activities, "it's almost like I don't have MS" and "let sleeping dogs lie." Denial, however, did not work for all. One respondent stated,

Denial, my family was just totally in denial. I don't like that anymore, I don't like people who are in denial.

After diagnosis participants collected information and then chose what information they would consider. For example, one stated that he stayed with the doctor who said "it won't kill you which is what I wanted to hear." Picking and choosing which physician, which opinion, and even whether or not to take medications afforded some a sense of control. By "taking charge" on their own terms, these participants were able to maintain a sense of wholeness and cope in the face of great challenge.

Fight Your Own Fight

The fourth theme, "fight your own fight," was based on participant descriptions of how to "be your own advocate" and taking charge. They acted as advocates for themselves in a number of ways. They asked, "What is there that I can still do that I like doing and carve that into my lifestyle?" Other techniques included,

Write stuff down, you can still read. Write the sequence of what you've got to do...You find a way to do the things that you like to do... writing out a list is a good idea to keep things straight.

One said, "I am not going to let this stop me," and another added, "I just figure out a way to do what I want to do." Aggressive exercise programs, modifying houses for wheelchairs, moving to a one-story home, and planning each day are examples of how they took charge.

Participants fought their own fight by learning about the disease since "knowledge is power" and "the more I know the more I can handle things as they occur." The courage and fortitude of these participants were exemplified in one person's statement,

If you don't fight for what is best for you then don't expect anyone else to do a better job for you than yourself.

Others said, "fight for what is best for you."

Some participants instigated lifestyle changes based on their symptoms and abilities. For others, lifestyle changes were forced upon them. One man negotiated with his employer until he was given a position that he could handle while another was forced to relinquish his position even though he tried to continue. Other participants learned to work around their symptoms and adjust their activities in order to do the things they most wanted to do.

Other Findings

One participant described how she

went off my Copaxone because I was suffering from heart palpitations. Turns out it was too high a dose of bee pollen that was causing that.

Some refused the medications because the physician would not assure them of its effectiveness, they were doing well at the moment, and the cost was a deterrent. Not all of their health problems were due to the MS; one had surgery for an abdominal aneurysm and another for lung cancer.

Respondents expressed strong feelings about health-care providers. They identified specific physicians who were "wonderful" and others whom they did not like. These participants also believed that their physicians made judgmental comments such as "you are lucky it is MS and not something else." They valued extensive

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knowledge about the disease and appreciated comprehensive treatment approaches as valuable and supportive. Some described the nurses in the physicians' offices and those on call as supportive, available, and knowledgeable. One, however, described how his hospital nurse "mix(ed) the medication wrong," causing him and his wife inconvenience and distress.

Discussion

The participants in this study had MS for various lengths of time and were experiencing mild to severe functional changes. However, MS had caused major lifestyle changes and they were no longer able to meet role expectations in the same way (Yorkston et al., 2001). They shared freely their feelings and reactions with the group. All but one seemed to have made peace with the diagnosis and were incorporating adaptive changes. Even those using denial made changes in their homes or aspects of their employment. Fatigue led them to refocus

their priorities, plan their activities, and choose carefully what they wanted to do.

Perhaps the most moving communication by participants was the feeling that they were not being heard. Their symptoms varied and were often misdiagnosed, but there seemed to be mutual agreement that the need for someone to listen nonjudgmentally was not only missing but also desperately needed. Not surprisingly, their emotional needs were unmet and ignored (Koopman & Schweitzer, 1999).

The devastation of symptom onset was dispersed with knowledge of their disease. All searched for information and knowledge; one noted, "Knowledge is power." This is consistent with other research indicating that not only at diagnosis but also with exacerbations there is an ongoing need for current and specific information (Baker, 1998; Miller & Jezewski, 2001). Even in the midst of denial, participants read pamphlets from the MSS and talked to other people. The more they understood their illness the better able they were to "pick and choose."

Picking and choosing allowed them to alter their lifestyles and, at the same time, maintain some control. They chose activities important to them; while denying the seriousness of MS, they made important accommodations and learned to prioritize their goals. This supported development of self-advocacy skills, the ability to take charge, and to "fight for what is best."

These participants described the variety of their symptoms and the length of time before diagnosis as a time of pain and discomfort, not only because of the symptoms but also because of the attitude and comments of health care professionals. This group felt unheard, invalidated, and dismissed as hypochondriacs, which added greatly to their distress. As they learned about MS and made appropriate lifestyle adaptations to the devastating symptoms, they learned to "fight" or advocate for themselves.

Nursing Implications

Although this study was limited by the design, small and convenient sample, variation in diagnosis length, and lack of participant review of data, the information from this study is important for nursing. There are a number of nursing implications based on participant experiences and feelings. The process of diagnosis was clearly difficult for these participants. Nurses must partner with the person with MS. Interventions need to begin when patients first seek medical attention and continue through the diagnostic process and adjustment period. Again and again participants identified the need for someone to listen. Nurses who come in contact with these patients need to pay attention and find the time to spend with them. Patients who feel heard experience validation. They are then able to begin establishing goals, setting priorities, and learning to advocate for themselves.

Referral to counselors and chaplains only provides a "seduction of reassurance" (Sabo, 2000). Not only are nurses educated to understand the experiences of patients, the symptoms of disease, and ways to intervene, but also they have frequent contacts with people in the healthcare system. They make a difference in outcomes by being available as counselors, educators, and coaches.

Patients experiencing the devastation of MS symptoms, even without a definitive MS diagnosis, need rehabilitative interventions for functional problems and ongoing emotional support (Koopman & Schweitzer, 1999). Active listening and attention can provide the security a patient needs to continue the diagnostic search, adapt to the illness, and learn to incorporate changes into personal and family lifestyles. These interventions increase patient self-management and enhance their self-advocacy.

Knowledge is seen as power, so nurses need to provide information and resources for participants and their families. Packets of information on appropriate reading levels could be available to give at the time of diagnosis. Discussion of medications, costs, and side effects needs to occur in a collaborative atmosphere, to support informed decision-making, and to assess resources for payment. Nurses can help patients learn to arrange daily activities to conserve energy while doing what is most important. Making lists, putting damp washcloths in the freezer, using a wheelchair at the mall, sitting instead of standing when possible, and appropriately timing rest periods are empowering skills.

It is important for nurses to identify interests and activities participants enjoyed before they began having symptoms and then help them design ways to continue these activities. Maintaining employment or evaluating the work situation to determine possible adjustments could support patient adaptation. Patients also need support and permission to advocate for themselves. Commending their strengths, validating their coping strategies, and teaching step-by-step problem solving and specific coping techniques and ways to self-manage their illness will enhance their adaptation.

Further Research

A longitudinal, experimental intervention study is needed to increase and support adaptation to MS and decrease suffering. Immediate and ongoing, easily available information is needed. Patients need a listener, a coach, and an advocate to help them chart their course. Interventions to increase their self-management, self-advocacy, and coping skills can improve quality of life. Interventions for spouses, partners, and family members could teach them to develop supportive partnerships with patients, thus improving coping, adaptation, advocacy, and management skills of patients and significant others.

Summary

Examining the "lived experience" of dealing with MS has reinforced the need for building partnerships between patients and their healthcare providers. Needing to be heard, dealing with the devastation of symptoms and unexpected symptom onset, and learning to advocate for self are requirements of learning self-management. Nurses must take the leadership in helping people manage their illness and navigate the healthcare system. The data gathered in these focus groups showed that people with MS are not only willing but also need to share their experiences. The data also identified patients' needs and nurses' roles in meeting these needs. These findings contribute to the knowledge and understanding of the needs of people living with MS.

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