Communication in Context: A Qualitative Study of the Experiences of Individuals With Multiple Sclerosis

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The purpose of this study was to examine an insider's perspective on communication in multiple sclerosis (MS), a disease of the central nervous system in which scattered lesions or plaques produce varying combinations of motor, sensory, and/or cognitive impairments. Qualitative research methods were used because they are designed to provide a systematic way of exploring complex issues, such as communication, that cannot be separated from the context in which they occur. Seven participants, all of whom had mild communication impairments, described their everyday experiences of communication and the impact of MS on these experiences. Themes derived via inductive analysis of verbatim transcripts included: watching the communication changes, it's about participating in my life, and communicating is unpredictable.

Using the World Health Organization model of disablement, the participants' communication impairments were mild. However, participants reported major lifestyle changes characterized by important limitations in communicative participation. Whereas some of the limitations were attributed to changes in speech and language, others were thought to be the result of changes in cognition, vision, mobility, and susceptibility to fatigue. Clinical implications include the need to develop assessment protocols and outcome measures that capture issues related to communicative participation in natural contexts and participation in society.

Key Words: multiple sclerosis, speech and language assessment, qualitative studies, disablement

The World Health Organization (WHO) model of disablement provides the rehabilitation community with a client-centered structure for organizing the consequences of chronic disease. It categorizes the disabling consequences of chronic disease as: impairment (e.g., loss of physiologic function, as with laryngeal spasticity), limitation in activities (e.g., a person's difficulty speaking), and restriction in participation (e.g., changes in involvement in life situations such as work) (WHO, 1999). Because this model integrates a medical model with a social model, it has been called a "biopsychosocial" approach (Frattali, 1998). This model frequently has been applied to the study of communication disorders (e.g., Rogers, Alarcon, & Olswang, 1999; Yorkston, Beukelman, Strand, & Bell, 1999; Yorkston & Kennedy, 1999). Its use has increased the recognition of the gaps in our knowledge. These gaps are particularly apparent in the area of participation: the field of speech-language pathology is only beginning to understand the consequences of chronic neurologic conditions on an individual's ability to take part in desired social roles.

If we are to understand communicative participation or the restrictions in participation that accompany chronic neurologic conditions, we must understand communication as occurring in context. People communicate in the context of their everyday lives. This includes the roles they choose or are expected to play, the circumstances in which they exist, and the community culture that defines their natural environments. Qualitative research methods are particularly well suited to the study of communicative participation because they provide a systematic way of exploring complex issues that cannot be separated from the context in which they occur. Qualitative research has been defined as "a set of systematic and interpretive practices designed to seek answers to questions that stress how social actions and social experiences are created and sustained" (Damico, Simmons-Mackie, Oelschlaeger, Elman, & Armstrong, 1999, p. 652). In-depth interviews
allow access to experiences of individuals and their stories about living with chronic health conditions.

Qualitative methods are also well suited to the study of multiple sclerosis (MS), a condition in which both the natural course and symptomatology are variable. Participants are free to describe their experiences over time, thus capturing the variability of the conditions and its symptoms. MS is a disease that affects the white matter of the central nervous system and is characterized by progressive neurological deficits, often with a remitting/remitting course (Sliva & Cohen, 1998). Because the scattered lesions or plaques produce varying combinations of motor, sensory, and/or cognitive impairments, symptomatology varies considerably from person to person. Further, MS is most common in adults of working age. Individuals with MS may choose to participate in a wide variety of communication contexts and play a number of different roles, including parent, spouse, friend, employee, volunteer worker, or homemaker. Both the neurologic condition and the context for communication may vary considerably across individuals. Both affect the lived experience of MS.

A variety of communication disorders have been identified in individuals with MS, including dysarthria, aphasia, and cognitive impairment affecting communication (Achiron et al., 1992; Arnett, Rao, Hussain, Swanson, & Hammeke, 1996; Kujala, Portin, & Ruutuainen, 1996; Lethlean & Murdoch, 1993; Olma-Lau, Ginsberg, & Geller, 1977; Wallace & Holmes, 1993). Self-report questionnaires about communication difficulties associated with MS indicate that approximately 25 to 45% of the respondents noted changes in speech and/or communication (Beukelman, Kraft, & Freal, 1985; Hartelius & Svensson, 1994). Much of the information in the research literature related to communication focuses on the level of impairment or limitation in activities. For example, when studying language impairments, the components of impaired naming, reduced word fluency, and poor sentence construction have been identified (Lethlean & Murdoch, 1993). In another example, studies of the speech impairment focused on the component of phonatory instability (Hartelius, Buder, & Strand, 1997). In 1994, a subcommittee of speech-language pathologists formed by the Consortium of Multiple Sclerosis Centers published a review of existing literature on communication in MS (Sorensen, Brown, Logemann, Wilson, & Herndon, 1994). They found that there are many “unknowns,” including information about the prevalence of various types of communication problems and the natural history of these problems with MS type and disease progression. Although not a focus of the 1994 review, restrictions in communicative participation are another “unknown.”

Cognitive deficits associated with MS have been studied more extensively than communication deficits. These cognitive deficits vary greatly and depend on the location, number, and activity of lesions and are correlated with increasing lesion load on MRI (Rao, 1995). In a meta-analysis of studies dating back to 1983, results indicated that neurocognitive impairment was evident in several areas, including verbal fluency, information processing speed, selected measures of memory, and cognitive flexibility (Zakian, 2000). Estimates of the proportion of individuals with MS experiencing cognitive difficulties vary depending on how the estimates are made. Estimates of cognitive deficits that are based on conversation or simple screening examinations are not sensitive to subtle changes and thus may underestimate occurrence. Self-reports of a large group of individuals with MS indicated that 38% reported significant cognitive problems (Sullivan, Edgley, & Dehoux, 1990). When neuropsychological testing was used to estimate the occurrence of cognitive changes, prevalence rates increased from 50 to 70% (Heaton, Nelson, Thompson, Burks, & Franklin, 1985; Rao, Leo, Bernardin, & Unverzagt, 1991). With a few notable exceptions (Foley et al., 1994; Wallace & Holmes, 1993), the impact of cognitive deficits on communication has not been studied.

The purpose of this study was to understand communication in MS by examining the insider’s perspective, a term used by those who study disablement to denote the lived experience (Peters, 1995, 1996). Taking the insider’s perspective places emphasis on the environmental and social contexts of communication and is particularly critical in the development of successful interventions for individuals with chronic disease.

**Methods**

Qualitative research methods that examine insider perspectives have contributed invaluable information that has shaped clinical practice and treatment in a number of health-related fields (Damicco, Otschlaeger, & Simmons-Mackie, 1999). One qualitative research approach that has been embraced by health-related fields is phenomenology, a means of investigating questions concerned with the lived experience (Benner, 1994). It guides the researcher to move from theoretical abstraction to the realities of those who have particular health conditions (Hafsteinsdottir, 1996). Phenomenology is an approach rather than a definitive research method with clearly outlined procedures. It is guided by the use of the subjective and first person experience as a source of knowledge (Maslow, 1966). The main theoretical premise is that the meaning of an experience can only be gained if it is viewed within the context in which it occurs (Paley, 1997).

The phenomenological approach involves gathering information from a number of individuals about a particular experience. It is assumed that reality comes in many perspectives, that people are experts on their own reality, and that when queried, people can reflect on and talk about their realities. Further, participants are assumed to be honest individuals who would not intentionally fail to reveal aspects of their experiences. The phenomenological research approach involves individual in-depth interviews about the topic of study. This approach uses guided interviews to engage participants in a dialogue with the investigators in order to inductively describe their lived experience without constraint of theory or clinical perspective (Colaizzi, 1978). Questions posed are broad and open-ended. This approach allows the participant to share the information he/she feels is most crucial. The nature of this
type of research leaves room for multiple interpretations of any given phenomenon. The researcher must identify the most illustrative yet parsimonious themes that honor multiple interpretations people have about living with the phenomenon under investigation. The methods for each study must be clearly and explicitly described because there are no universally accepted procedures that dictate the specific methods used in a phenomenological study (Mischler, 1979).

Participants

Seven participants were recruited through medical center clinics, local consumer organizations, and by word of mouth. As described in Table 1, most participants exhibited mild communication problems. Most were women between the ages of 45 and 55 years who did not require assistive devices for walking. At the time of the interview, 3 were employed, 3 participated in volunteer work, and 1 was retired because of disability associated with MS. Years postdiagnosis ranged from 2 to 15, with a mean of 7.6 years. After the purpose and procedures of the study had been described, participants signed written consent forms for the interviews and were told that they could end their participation at any time.

Interviews

Participants were asked to describe their everyday experiences of communicating and the impact of MS on these experiences. The interview was organized around broad topical areas related to communication and MS. A number of techniques were used to promote an open discussion (Westby, 1990). First, the purpose of the interview was carefully explained. This explanation introduced the notion that the participant was the expert and that the interviewer wished to understand what it is like to live with MS. Interviews started with “grand tour” questions such as, “What is a typical day like for you?” From this starting point, the interviewer guided the participant to fully describe communication experiences. The interviews yielded information about communicative situations, the physical environment, and potential communication problems. Questions were phrased in a neutral manner, attempting to reduce potential bias and presuppositions. “Loaded” questions were purposely avoided. For example, the question, “What communication strategies work for you?” presupposes that communication problems exist and that there is something called “strategies” that should be used. A more neutral question might be posed: “What’s communication like for you?” Participants were encouraged to elaborate on communication issues in order to provide a context for understanding commonly used terms such as “fatigue” or “confusion.” For example, the interviewer might have requested a more complete definition by saying, “Tell me what you mean when you say that you are confused. If I were in the room when this happened, what would I see?” Encouraging the participant to paint a vivid picture gave information about communication tasks, the situations in which they occurred, how the participant felt about the situation, and how he or she coped with barriers encountered. Throughout the discussion, the interviewer would echo what the participant had said. This process allowed misunderstandings to be clarified, helped to develop a shared vocabulary, and suggested to the participant that his or her comments were important to the interviewer.

Two of the authors conducted the 1- to 1.5-hour initial interviews in a private conference room at the University of Washington School of Medicine. One person acted as the “lead” in the interview and posed the questions. The second person was present to take field notes and make

<table>
<thead>
<tr>
<th>Identifier</th>
<th>Age (Current/At Diagnosis)</th>
<th>Gender</th>
<th>Years Post-diagnosis</th>
<th>Primary Communication Problem</th>
<th>Ambulation Assistance</th>
<th>Occupation</th>
<th>Employment Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>FT</td>
<td>55/42</td>
<td>F</td>
<td>13</td>
<td>Mild cognitive changes</td>
<td>None</td>
<td>Elementary teacher</td>
<td>Retired; volunteers</td>
</tr>
<tr>
<td>ST</td>
<td>55/51</td>
<td>F</td>
<td>4</td>
<td>Mild cognitive-communication deficits</td>
<td>Cane</td>
<td>Elementary teacher</td>
<td>Retired; volunteers</td>
</tr>
<tr>
<td>WL</td>
<td>45/42</td>
<td>F</td>
<td>2.5</td>
<td>Mild ataxic dysarthria</td>
<td>None</td>
<td>Coordinator of volunteers</td>
<td>Unemployed; volunteers</td>
</tr>
<tr>
<td>SP</td>
<td>52/40</td>
<td>F</td>
<td>12</td>
<td>Mild-moderate cognitive-communication deficits</td>
<td>None</td>
<td>Project manager</td>
<td>Retired on disability</td>
</tr>
<tr>
<td>DS</td>
<td>29/24</td>
<td>M</td>
<td>5</td>
<td>Mild cognitive-communication deficits</td>
<td>None</td>
<td>Doctoral student; computer programmer</td>
<td>Employed</td>
</tr>
<tr>
<td>VB</td>
<td>46/31</td>
<td>F</td>
<td>15</td>
<td>Mild dysarthria</td>
<td>Wheelchair at work</td>
<td>Banking executive</td>
<td>Employed</td>
</tr>
<tr>
<td>RC</td>
<td>48/26</td>
<td>F</td>
<td>2</td>
<td>Mild cognitive-communication deficits</td>
<td>None</td>
<td>Receptionist</td>
<td>Employed</td>
</tr>
</tbody>
</table>

Mean 47/39 7.6
observations. Follow-up interviews were conducted after preliminary analysis of the initial interview to further address topics of interest, including the changes in communication, effects of fatigue, the decision to leave employment, and so on. Following each interview, the interviewers discussed and made notes about the salient topics discussed by the participant. Sampling continued until the same or similar kinds of information were spontaneously introduced or comfortably elaborated on in subsequent interviews, as is standard practice in phenomenological research.

**Analysis**

Interviews were audiorecorded and transcribed verbatim. The accuracy of the transcripts was verified by one of the interviewers, who also transcribed the small proportion of the tapes that were difficult for the transcriber to understand. The data analysis was consistent with the principles outlined by Benner (1994). Each transcript was read multiple times in order to appreciate the essence of the entire interview. The interviews were then re-examined several times more in order to begin the process of identifying portions of the interview that expressed an idea or opinion about the experience of communication. Code words were attached to those ideas or opinions, using the Ethnograph software package (Seidel, 1998). The Ethnograph is a computerized indexing system that enables rapid retrieval of text that has been organized into meaningful segments. It also enables documentation (an audit trail) of how data were organized.

Initial codes for this investigation were concrete and descriptive, using the actual words of the participants themselves. For example, if a participant talked about visual difficulties, this portion was coded as “vision” without any interpretation as to how it related to communication. However, as the transcripts were read and reread, common themes could be interpreted. For example, after re-reading the transcripts several times, it became evident that participants often described communication experiences that had occurred in the past (initially coded as “the past”). They talked about the experience of communication before having multiple sclerosis (the past) and after having multiple sclerosis (now). This information was then interpreted to reflect a change in communication and the theme “communication participation has changed” emerged.

The initial coding was completed separately and in joint sessions by the first two authors. Summary descriptions of each interview were then drafted in order to highlight similar and different themes among the interviews. Initial interpretations were presented to a team of six colleagues, all of whom had doctoral training in qualitative methods, who have had several years of experience conducting research using a phenomenological approach. Each colleague brought a unique perspective to the process and moved the analysis forward beyond any one person’s preconceptions. The trustworthiness of analysis was enhanced by the research team’s commitment to challenge each other’s biases and honor the perspectives of participants. The process continued until all agreed that the generated themes accurately reflected the information provided by the participants and served the purpose of the study. The credibility of the findings was validated by further discussion with the participants as they returned for follow-up interviews (Benner, 1994). A summary of the initial interview was reviewed with the participant, and the participant was then asked to comment on the validity of the interpretations offered. These comments were then reviewed, and themes were altered if necessary to reflect participant opinions. The remainder of the follow-up interview focused on changes that may have occurred since the original interview and questions that specifically addressed gaps in the initial interview. This information was collected for future analysis.

**Results**

Three major themes and eight subthemes emerged from the analysis of the information shared by the participants in this study (see Table 2). The first theme, *watching the communication changes*, included *life is not what it was*, and *acknowledging the change in communication* as subthemes. The second theme, *it’s about participating in my life*, included *participation is important*, *communicative participation has changed*, and *communicative participation is limited by many factors* as subthemes. The factors affecting communication are delineated below, and each factor is illustrated by an example provided by the participants. The final theme, *communication is unpredictable*, included the subthemes *communication problems are variable*, *people treat you differently*, and *old strategies fail*. Direct quotations from the participant interviews are used to illustrate how the themes derived in this study captured the participants’ experience of communication with MS.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
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<tr>
<td>Watching the communication changes</td>
<td>Life is not what it was</td>
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<tr>
<td></td>
<td>Acknowledging the change in communication</td>
</tr>
<tr>
<td>It’s about participating in my life</td>
<td>Participation is important</td>
</tr>
<tr>
<td></td>
<td>Communicative participation has changed</td>
</tr>
<tr>
<td></td>
<td>Communicative participation is limited by many factors</td>
</tr>
<tr>
<td>Communication is unpredictable</td>
<td>Communication problems are variable</td>
</tr>
<tr>
<td></td>
<td>People treat you differently</td>
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<td></td>
<td>Old strategies fail</td>
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Watching the Communication Changes

The participants gave clear insights about their experiences in a variety of communicative situations. Even those with the mildest communication impairments appeared to be intensely aware of these changes. VB experienced cognitive communication problems associated with her job as a banking executive. She stated, “I don’t know what to expect, it doesn’t happen all of the time, but when it happens I know it.” Participants framed their comments around the themes that life was not what it was and that acknowledgment of the change was difficult.

Life Is Not What It Was. Participants described communication changes by comparisons with the way things used to be. For example, FT described in great detail her communicative experience as a teacher before MS “forced” her to retire. She elaborated:

Names don’t come as quickly as they used to. I used to walk into a class at the beginning of the year and be with the class in the morning and by noon you knew the names of the students. You know, I noticed it took me the first day and a little more. Like walking in [her former student’s] class, I don’t know the names of all of those students, like I would have in the past.

Another participant, SP, acknowledged that she was very frustrated by her “confusion.” She made comparisons with the past as a way of telling others that she had not always been this way. She was describing her experiences at work when she said,

I kept wanting to say I’m not dumb. I minored in math....And I started in computers 20 years ago, with the punch cards. Yeah, that was long ago. But I was suddenly having problems even remembering where I filed things....but prior to that I had a rather nice, a job I really liked.

For others, making comparisons with the past was a way to convey knowledge of their declining abilities to communicate. Whether this was apparent to others or not, it was a real concern for the person with MS. For example, DS used a comparison to indicate that for him his writing problems were real. He stated,

I know it’s different than when I used to do it. I wrote a hundred page master’s thesis in a weekend. And sure it was a lot of work, but I didn’t feel like I was struggling like I do now.

Acknowledging the Change in Communication. Most participants identified a single event that solidified for them the realities of their cognitive communication changes. For example, DS described his oral qualifying examinations as the event that lead him to concede the effect of MS on his communicative performance.

I can’t see my own slides, and here I am talking with many who I’m trying to impress, and I’m pausing sort of frequently. And it sounds like, at least from someone who doesn’t know any better, that I don’t know what I’m gonna say. When in reality, I just can’t see that word that I’m trying to spit out. I’m just having trouble stumbling through it.

RC told of a situation at work. When she was transferred to a receptionist position, she was unable to learn her duties. She said,

I’m thinking, my God, am I always going to be this way? Is this always going to be where I can’t function well enough, physically or mentally, to comprehend anything new and take it in, adjust to it and make it work?

Acknowledgement of change was troublesome. She stated,

So I know now that I will not ever again take on a huge undertaking of things I don’t know. It’s not worth doing it to yourself—very difficult. If I had known what was going to happen a year ago, I never would have done it. It’s pretty devastating, professionally, to fail.

ST described retirement from teaching, a job she loved, as the event that obliged her to acknowledge changes. She stated,

But I did have to stop teaching and that was like the admission, when I finally had to look at myself realistically and say okay this is your disease, this is your battle, how are you going to best accommodate it? You can’t do, physically or mentally, what you loved to do, and that’s been my biggest challenge right now.

For SP, the realization of change came while grocery shopping. She had been on a meatless diet as a health maintenance activity. She told of coming home one day with 23 pounds of meat that had been on sale. She said, “I don’t know if it was an impulse. It was acknowledging to myself that I was confused. It was something part of me couldn’t pass up, but another part of my brain knew that we don’t eat this.” Another moment of acknowledgment for SP came when she watched her husband complete social security disability application forms. She stated,

[The form] asked him what is changed, what’s the difference? And he appeared to be so aware of what was going on and what was happening in my head and my life and he wrote this down. It almost brought tears to my eyes.

WL also indicated that completion of social security forms was an uncomfortable moment of acknowledgment as well. She stated

[The form asked you to] describe in great detail how each ailment affects your life. And it’s amazing how you know I’ve really adapted to so many of these problems, that I don’t even think of them really as being problems....The voice thing, I guess, I’ve gotten kind of used to. And the eyes, the vision problems. Yeah, I mean those I’ve pretty much adapted to, and I’m used to them you know, so I don’t real think of them as being major problems, but
writing about this stuff in great detail, I've found that I was doing worse.

Most participants found acknowledging the change difficult. ST summarized her reactions to change in the following statement: “It’s not easy because the change I go through is more and more limiting, and I simply don’t want to be limited.” Thus, participants acknowledged changes in communication and gave detailed descriptions of situations where these changes were difficult and troublesome.

It's About Participating in My Life

Concerns about communication focused mainly on issues of participation. Communicative participation involves playing the roles and doing the things one wants to do and involves communication within the context of one’s everyday life.

Participation Is Important. Participation by the informants took many forms, including working, volunteering, taking part in educational programs, and maintaining friendships. Continued participation in the face of MS was important. WL stated, “I don’t want my life to end just because of this. You know I want to overcome as much as I can and keep living. I think it is so important.” WL had quit her job and remained unemployed after the onset of mild dysarthria that resulted from her MS. Within 2.5 years, she had moved from the role of director of volunteer services at a conservation organization to volunteer, to living on her savings. At the time of the interview, she was planning to sell her photography at art fairs. When describing the consequence resulting from changes in her communication she stated,

Volunteer work is a much less threatening because I could tell them [about the MS] and they’re not going to not hire me because of it. Yeah, the employment is probably the only real thing. You know, and even going out and selling my photography is not going to be that much of a problem because I can be more open about it. I’m an artist!

Thus, she redefined herself by constructing a role in which she could participate that did not require flawless speech. She had a hopeful attitude when describing goals and objectives she was interested in pursuing.

Communicative Participation Has Changed. Most participants reported substantial changes in their pattern of participation, particularly in work and friendships. Four were unable to work because of the MS. For both FT and ST, former elementary school teachers, this represented a major loss. ST stated, “Education was my life.” When asked what she missed the most, FT indicated, “I would still like to be teaching.” ST echoed the same thought when she responded, “Working with kids. Professionally, having my own classroom... and maybe that’s because [my husband] and I don’t have children, that I can focus on them so well. I miss that horribly.” WL had made a decision to change jobs before she was diagnosed with MS. Volunteer work then became a priority for her. She stated, “I’ve done volunteer work since I was like 16. And it’s always been a big priority for me, and it still is. And I felt like without working I need to at least do something useful.” For others, particularly VB, a banking executive, work was so highly valued that she expressed fears about her well-being if she were to be unable to work. She indicated,

You know if I’m home, like when I was home for that 3 weeks when I was recovering and all that, I got really depressed. I get depressed if I just sit around and feel sorry for myself. Work is good therapy. I have definitely found that to be true, if I stay home I get depressed. I am just as tired.

VB was willing to sacrifice many other aspects of her life in order to maintain employment. She indicated, “It costs me having a life outside of work sometimes, because I can pretty much exhausted, (starts to cry)... I do like working. I am a strange person, I actually like working.”

SP, a former project manager, clearly enjoyed her job until cognitive changes caused her to “struggle” in performing the most basic clerical tasks. She subsequently retired on disability, expressing a sense of relief when she stated,

The more frustrated I get, the more confused I get, and I just—it’s kind of like a round robin. I didn’t realize how much had been taken off my shoulders until the day I walked out the door.

Despite this apparent release from her struggle, she indicated that by not working she also lost the opportunity to communicate with friends. She stated,

All my friends have been through work and we had made personal friendships, had gone to lunch... basically at this point I don’t have any friends. There’s my husband, he supports us socially. You know his work, his social stuff, but that’s definitely his. It’s not somebody I would call.

Most participants reported a general change in friendships. Some felt that their friends were responsible for the changing pattern. For example, WL stated, “I’ve had a number of people that have totally popped out of my life and the only thing I can think of is, that, it must be really uncomfortable being around people that are not well.” At other times, participants attributed the changes in friendships to their own symptoms of MS. For example, FT attributed the changing friendship pattern to her slowness and susceptibility to fatigue. She expressed relief in no longer going on short trips with friends when she told her husband, “Now we can go at our own pace and I won’t feel like I’m, you know, encumbering anybody by slowing down.” In another case, FT reported that she was reluctant to go shopping with a friend because, “she’s five foot one and she goes like a house afire and I’m feeling like I’m holding her back.” For DS, changes in friendship patterns were attributed to his self-imposed health maintenance behaviors. He stated,

So every time someone wants to go out and get a pizza. That happens at work all the time. Where everyone’s at lunch, and either I go and I’m the guy having lettuce in the corner or I just don’t go.
In summary, patterns of participation had changed in work, social situations, and life in general for the study participants. The general trend was for decreased participation in valued roles such as occupation and friendships.

**Communicative Participation is Limited by Many Factors.** When participants spoke about situations where communication was required, they frequently described limitations associated with MS that hindered participation. These limitations fell into the following categories: speech, language changes, cognitive communication changes, fatigue, and visual changes. Although not all of the participants experienced changes in every category, the categories represent a range of important potential barriers to communicative participation.

**Speech and language changes.** WL, who experienced mild ataxic dysarthria, found that her speech problems limited her participation. She suggested an incongruity between what she is thinking and how she sounds when she stated, "I feel like what is going on in my head is not what is coming out of my mouth." She described her speech in the following ways, "I couldn't speak quickly, and I couldn't speak real clearly," and, "I'm talking at a lower volume." She also suggested, "People just really couldn't understand me. They either couldn't hear me, or they couldn't understand me, or both."

Several participants expressed difficulty with word-finding and verbal or written organization. For example, when describing her word-finding difficulties, SP stated, "They just don't come out of my mouth. I don't know another way to put that, and I can't speak my entire mind." FT suggested more subtle changes in verbal efficiency. She stated, "I have noticed in my communication skills, I hesitate and have to think more than I used to." She did not clearly attribute these changes to MS. She stated,

I think it is generally in the conversation many times with my husband or friends, you'll sort of have a brief lapse, in the middle of the sentence and, but again is that hormones and midlife? Who knows?

DS associated his word-finding problems with cognitive changes. He stated, "The word-finding, the more cognitive stuff, is mud I have to slog through." DS also clearly described limitations he experienced in handling auditory information. He indicated,

Someone will ask me a question and I will hear it, but I won't necessarily process it, and so I catch myself repeating that acoustic signal again, and then deriving meaning from it after like the fifth time I've sort of repeated it to myself."

When describing the writing associated with his doctoral program, DS commented, "It's horrible....It's really difficult to organize and communicate the ideas. Really hard."

In summary, participants described various changes in speech and language that limited their ability to be understood and to speak. These included dysarthria, voice disorders, word-finding difficulties, problems with verbal and written organization, and problems handling auditory information.

**Cognitive communication changes.** Changes in communicative participation were frequently attributed to cognitive limitations. For example, FT described in great detail why teaching had become so difficult for her. She stated,

I think it is just overload in a job like this when you are dealing with 25 first graders and the demands of the day, that sometimes, you know little things would get lost or you become forgetful or that kind of thing.

ST also described how the demanding task of managing an elementary classroom was made even more difficult by her cognitive communication changes. She stated,

To focus on one conversation, it took a great deal of concentration. As a classroom teacher, I found I wasn't, because my hearing was being affected, that I wasn't picking up on a lot of things that were going on that kids would say to me, because I'd be involved with someone else.

Handling multiple activities, a feature that had been a routine part of her life, was now difficult for SP. She described how easy it was to get “off track” when she said, “Well, I hope not to be interrupted. If I'm interrupted, or something like that I can't, I go off to whatever the interruption is. And that will play in my head for an unbelievably long time.”

Several of the participants suggested an association between cognitive changes and fatigue. For example, FT stated, “I think maybe there has been a diminishing cognitive function and the fatigue maybe overlays that, because you are tired, things don't come as quickly as they used to.” ST stated when describing her experience in the classroom, “I was finding that it would take more and more concentration to pick up on those things that I didn't have to concentrate quite so hard on, and because of that intense concentration, it's fatiguing.” RC, who continued to work as a receptionist, associated fatigue and cognitive changes when she said,

I just get real tired and don't, I don't think I'm as quick mentally. I find myself probably looking up more phone numbers, more directory information. I can't function in anything except sitting right here. I couldn't absorb anything new.

Thus, participants describe a variety of cognitive changes that limit communicative participation, including problems with attention, concentration, and new learning. These cognitive changes were frequently associated with fatigue.

**Fatigue.** All but one participant described fatigue as being a pervasive part of their lives, affecting both the ability to communicate and opportunities for communication. WL, the participant who suggested that fatigue was not a major issue for her, also indicated that she routinely slept 12 hours per day. When describing the impact of fatigue on activities such as reading, DS said, “Everything seems really heavy, and you can make that analogy for the mental processing and the cognitive processing. Where just reading something is a real burden for whatever reason.” VB, a banking executive, stated, “when you get tired, there..."
are cognitive problems and fatigue, you don’t think as clearly, it doesn’t mean I can’t do my job, but I think it is a struggle.”

Fatigue limits the opportunities for communicative participation. In fact, FT stated, “It dictates my life.” She indicated that fatigue entered into all of her life plans and decisions. When asked about how communication has changed, she began to tell a story of the decision she and her husband recently made when they bought a dining room set. The discussion revolved around the size of the table that they were going to buy. She stated,

Entertaining and our social life has dramatically changed, ‘cause I just don’t have the steam to fix dinner, or to do a lot of things. So do we have to have six chairs? Will we have six people for dinner? I can’t do that. But I miss that part of it.

Thus, a valued communication opportunity was no longer available to her. She also felt that fatigue limited her ability to participate in volunteer work. She stated, “I would love to volunteer different places, and expand myself, but I’m afraid to, because I don’t want to make a commitment and then go, oh I am just exhausted, I can’t do this.” ST also indicated that social interaction had been limited by her fatigue. She stated,

I was minimizing my contacts. I found that social interactions were very exhausting...so I couldn’t really be away from the house. And social situations in which a lot of interaction was required was very difficult for me.

For ST, fatigue also affected the quality of communicative interactions with her husband. She stated:

Everything seemed to be magnified and I was just able to do less and less and less, I would find at night that [my husband] and I, we’d just sit and look at one another, rather than converse. And television became more of a focus point because it filled that emptiness.

Thus, fatigue was viewed as a barrier to communicative participation because it impeded cognitive communication abilities and decreased the opportunities for communication in work and social settings.

Vision. Although several participants reported minor problems with vision, DS indicated that change in vision was one of his most troublesome symptoms. He described these changes as a “timing” problem when he said, “Someone throws a Frisbee, I try to grab it at and I miss it by like a foot, because I just don’t process that as quickly as I used to.” He indicated that the symptoms “come and go” and it was difficult for him to pick up “small detail out on a large space.” Vision problems limited his ability to perform some of his duties as a teaching assistant. He reported,

I’d write stuff on the board and I couldn’t see it. If someone asked me a question about, you know, what does that say? And I’d have to sort of trick them into pointing me to where on the board. I couldn’t see my notes, stuff like that. This was all prior to actually coming out with the disease. I tried to keep it a secret as long as possible.

His visual problems also limited social interactions. He indicated times when he couldn’t “really see the person” and conversations felt like “you were talking to a mannequin.” He described a situation in which transient vision problems altered communication when he said,

I lived close to the campus, and so I walked to campus and back, and after about a block I’ve lost my vision. So even seeing people on the streets, recognizing people, people would say hi to me and I would pretend to ignore them a lot because I didn’t know who it was or who said it.

Thus, visual problems were reported to hinder obvious activities such as reading but also some important aspects of interpersonal communication.

Communicating Is Unpredictable

In addition to limitations in communicative participation, participants indicated that communication was no longer as they had learned to expect it. This unpredictability made it difficult to anticipate or prepare for communicative interactions. Participants spoke of unpredictability that did not relate to the long-term course of the disease but rather to issues of day-to-day variability of communication, being treated differently by people, and the fact that old strategies for communication no longer worked well.

Communication Problems are Variable. MS is a variable disease with attacks or exacerbations associated with an increase in symptoms, followed by remission where the symptoms lessen. Participants extended this variability to issues of communication and suggested that some days are better than others. FT, who was 13 years postdiagnosis, stated,

Now I don’t think [about] unpredictability as far as waking up tomorrow morning with an attack. That sort of has left me. I don’t carry that around. But I do carry the fear of how am I gonna be able to handle a situation, you know, if I get tired.

DS reiterated this variability when he indicated that difficulty with communication “comes and goes similarly to that of the physical problems....If I’m tired, or fatigued or it’s hot, then, yeah, I’d probably have more stunted speech or erratic speech.” He indicated that this variability was particularly difficult to handle in the workplace because his supervisors were not aware whether he was having a good day or slogging through what he referred to as “cognitive mud.” He stated,

I’m often placed in a role where I have to perform at a certain level, and some days that might be really easy, some days it might not. When I don’t perform at that level it’s not because I’m stupid; it’s not because I don’t get it. It’s because today I’m slow, and people don’t remember that.

Others suggested that they could not predict “what will come out” when starting to speak to someone. SP described her reluctance to start conversations when she said,
“I cannot be terribly certain that half the words won’t be gone. And something will, in that case, something will come out that isn’t what I meant.” VB suggested that she was not always satisfied with her responses to co-workers’ questions. She stated that unless she monitored herself carefully, “I will give them kind of a black and white answer that isn’t well thought out.” She suggested that accurate and appropriate responses were no longer automatic. Rather she stated, “I notice a difference just in my communications, just that I have to concentrate on what I am saying to someone and I think more about what I’m saying.”

**People Treat You Differently.** In addition to the day-to-day variability in communication abilities, several of the participants felt they were treated differently because of the MS. Because this treatment varied from one person to another, it was also viewed as a source of unpredictability. VB, describing those in her workplace, said, “I think basically you get stereotyped and they see you as your ailment and they don’t see you for yourself.” When she described co-workers’ reaction to her disclosure of MS, she commented, “But the reactions of people, it’s always interesting. Some people are very warm and are very understanding and just ask questions. Some people say nothing. The people that say nothing bother me, it’s very callous.”

It was difficult for some of the participants to foresee the responses of others. When asked about how communication had changed, FT responded people would walk off and leave her behind. She indicated that an acquaintance, who was also diagnosed with MS, had called her shortly after FT’s diagnosis and told her, “You’ll find that people will walk off and leave you.” Although she did not believe it at the time, FT later found it to be true. She described a situation where she was going to lunch with some fellow teachers. She stated,

> When we were teaching together, the three of us, we would come down for lunch and pretty soon I would notice, that they were you know, steps ahead of me. I was just kind of plodding along. If you can’t keep the pace, you know, we don’t have time for that.

VB made a similar observation when she stated, “I notice that with my friends when I go out to lunch with somebody, I walk across the street, most people my age walk faster than me, and they just walk ahead of me.” In the following description, VB also told of a different response from her grandmother, one that was interpreted as empathic and supportive. VB stated,

> She’d walk with me and she would walk with me at my pace. That was just wonderful. Even though she was 80 years old, she could walk faster than I could when we were walking, so she would stay at my pace. She would always do that, to me that’s supportive, when people do little things like that and don’t make a big deal out of it, I really notice that.

Participants with changes in speech appeared to feel the responses of others most intensely. WL, who experienced a mild dysarthria, felt that the changes in her speech were a signal to others that something was different. She stated, “I guess feeling like anytime I talked to anybody, there was this big sign that said, ‘There’s something wrong with her!’” She described in detail an unpleasant interaction with a store manager when she “wasn’t talking well.” She stated,

> And I remember stumbling, just stumbling over my words talking very slowly, and she was obviously in a big hurry, and she wanted everything real quick and I just couldn’t do it. She just looked like I was driving nuts, like I was really frustrating her and bothering her and, you know, I ended up getting what I wanted which was good, but she really was cutting me short, and yeah, it was kind of unpleasant.

Thus, even when the transaction was successful, the fact that the manager treated her in a way that she did not expect was distressing to WL. In fact, even though the exchange had occurred 2 years earlier, it still elicited intense feeling from WL.

**Old Strategies Fail.** Participants also suggested that old strategies for interacting with people could no longer be expected to work well and that new strategies may need to be developed. After her encounter with the impatient store manager, WL speculated about adapting a new strategy that would involve acknowledging her communication difficulty. She stated, “I was going to say to people, ‘I’m sorry I have a voice disorder, please be patient with me.’ You know, and I think it was after that incident actually that I realized that I needed to do that.” WL felt that other unsatisfactory communication interactions could have been resolved if she had been more assertive. She described a telephone call from a telephone solicitor in the following way,

> My voice was not good. It was right after I had taken my evening pill. My voice is usually kind of bad by then until the medication kicks in. And I was very unassertive. I should have said I am busy I can’t talk to you, good-bye. But I didn’t because I wasn’t talking well and I just was kind of stumbling and she was a fast talking salesperson. Oh, so it was bad and I got off the phone and I was real angry with myself. But I realized that part of it was just because I couldn’t really get a word in edgewise. You know I wasn’t talking well enough to be quick.

Although she indicated that assertiveness is an important strategy, WL also suggested that it was difficult to adopt an assertive demeanor with a communication problem. She stated, “Part of it is just not being assertive enough, but somehow when I don’t have good voice I don’t feel like I can be. You know, which is just a mental thing.”

VB reiterated the difficulty of adopting a strategy of assertiveness. Her advice to others with MS who wish to continue working was “to communicate” with the people you work with and “be assertive.” However, when describing the difficulty she was experiencing in communicating with supervisors at work, she indicated that the thing that was most difficult for her was “to be assertive” about the accommodations she needed such as a flexible work...
schedule. Thus, the individuals interviewed for this study suggested that old strategies need to be modified and that new strategies could be imagined and described. However, none of the participants interviewed appeared to endorse the success of these new strategies.

In summary, participants indicated that communication is unpredictable because it varies from day to day, responses of others vary from one person to another, and one can no longer rely on old communication strategies.

Discussion

The Insider's Perspective

Participants gave clear insights into their experiences in a variety of communicative situations. For the most part, communicative impairment was mild both by self-report and impression of the interviewers. Participants viewed changes in communication from the perspective of participation. Thus, when responding to the question “what’s communication like for you?” they spoke of interactions they could no longer engage in and the roles that they could no longer play because of the consequences of MS. Although some mentioned communication impairment in passing, the focus clearly was on communication activities in social situations and contexts.

Although their communication impairments were mild, participants reported major lifestyle changes characterized by important limitations in communicative participation. These limitations were the result of a number of factors. Whereas some of these factors related directly to communication, such as mild changes in voice and articulation, others did not. Fatigue was an issue raised by all participants. Some hesitated to take part in volunteer work because they couldn’t predict their daily level of fatigue. Others felt that social relationships were difficult to maintain because they couldn’t shop, go on short trips, or host dinner parties because their energy level was low. Mobility limitations made maintaining friendships difficult. Participants indicated that they “couldn’t keep up” with friends on outings. Visual impairment caused one man difficulty in recognizing people as he walked by them. This was interpreted by his friends as being “ignored” and consequently led to changes in social communication. Participants also spoke about the unpredictability of communication. Both their communication ability and capacity to participate varied from day to day. They felt that old communication strategies no longer worked well. Everyday communication situations were unpredictable because responses of others were “different from the way they were” and varied from person to person.

These findings emphasize the value of communication competence in society. Even when communication impairments were relatively mild, participation was greatly affected. When communication abilities are compromised, individuals can become “marginal” members of society. As is clear from the experiences of the participants, changes in social interaction occur and communication opportunities diminish. Familial and vocational roles may change and the person with MS is often overlooked and replaced by individuals that are judged to be competent communicators (Lubinski, 1995).

Clinical Implications

The WHO model of disablement previously described is increasingly used to focus communication intervention efforts. Assessment or treatment planning involves evaluating selected consequences of MS. In a traditional interpretation of the model, communication impairment exists because of an underlying condition or disease process. An impairment such as spasticity in the oral articulators leads to limitations in the activity of speaking that are characterized by slow, imprecise speech (dysarthric speech). This limitation in activity in turn leads to limitations in the ability to take part in desired roles (participation limitations). Too often, this model is interpreted as a unidimensional, unidirectional one, starting with the communication impairment that leads to limitations in communicative activities that in turn leads to limitations in communicative participation. This linear model with impairment as the starting point is reinforced by the fact that most of our assessment tools are directed at understanding the impairment.

The insider’s perspective offered through this study suggests a different interpretation of the components of the WHO model. Figure 1 illustrates this alternative view. Because insiders focus at the level of participation, the model is depicted as a pyramid with communicative participation at the top. Placing participation as the starting point is important because this may be the natural perspective of the insider. Further, failure to appreciate this viewpoint can interfere with the rehabilitation process. The point can be illustrated with a comment made by one of the participants as she walked down the hall after the interview. Her gait was unsteady. As she commented on her slowness, she indicated that she had been to a physical therapist but would not return because he wanted her to do balance exercises (focusing at the level of impairment) and she wanted to resume her hobby of hiking (focusing on participation). It’s clear that the therapist and the patient were viewing the consequence of the same condition from different viewpoints. Failure to appreciate the other’s point of view disrupted this therapeutic relationship.

The model depicted in Figure 1 also suggests that limitations in communicative participation do not arise solely from the impairment of the speech and language production system. Rather, they may arise from many types of impairment, including fatigue, motor, and visual symptoms. Failure to appreciate the many factors limiting communication participation will compromise clinical service. In focusing assessment and intervention solely on speech and language impairment, many barriers to participating in effective and satisfying communication are overlooked. For example, reports of fatigue should signal the clinician to explore issues related to communicative and cognitive function, because fatigue and cognitive or communicative changes are frequently associated. Intervention may include cognitive and communication strategies that enhance the ability to cope with the effect of
fatigue. Failure to appreciate the many barriers to participation may also lead to an underestimation of the extent that communicative participation is restricted. As suggested through this study, even relatively mild communication impairments lead to noteworthy changes in communication participation.

If clinicians wish to focus on communicative participation, they face a number of challenges. The first challenge is to develop assessment protocols that capture issues related to communication in context. Although the guided interviews and in-depth analysis procedures are not appropriate for routine clinical use, aspects of the interview techniques are clinically relevant. Asking the right questions in the right ways (Westby, 1990) can be a useful way of directing intervention. The second challenge faced by clinicians when attempting to enhance communicative participation is the measurement of treatment outcomes. Outcome measures focusing on communicative participation are becoming available (Garrett, 1999). Garrett’s review suggests that these instruments are a means of obtaining information about factors such as engagement in positive relationships, participation in meaningful life activities, levels of autonomy and independence, and enjoyment of life. Many of these are global measures of quality of life, mood, and activity level. Investigations are needed to assess whether or not these global measures are sensitive to changes in communicative participation. There remains an urgent need to develop measures that reflect the quality of communication participation in adults with acquired neurologic communication disorders.

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