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The use of Focus Groups to Characterize Symptoms in Persons with Multiple Sclerosis

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Multiple sclerosis (MS) is a chronic neurological disease, often first identified in young adulthood (Disanto et al., 2010; Herndon & Greenstein, 2006). Relapsing-remitting (RRMS) subtype, the focus of this study, affects 85% of those with MS (Confavreux & Vukusic, 2006; Spain, Cameron, & Bourdette, 2009). Symptoms of MS are variable and unpredictable (White, White, & Russell, 2008). The myriad of symptoms may be due to multifocal and simultaneous involvement of numerous central nervous system regions responsible for discreet neurological functions (Miller & Allen, 2010; Newland, Naismith, & Ullione, 2009). Previous studies have primarily used the quantitative approach and focused predominately on single symptoms (Beiske, Pedersen, Czujko, & Myhr, 2004; D'Alisa, Miscio, Baudo, Simone, Tesio, & Mauro, 2006; Newland, 2008; Newland, Naismith, & Ullione, 2009; Svendsen, Jensen, Hansen, & Bach, 2005). In contrast, few published studies to date addressed symptom clusters or the co-occurrence of a set of symptoms in MS (Motl & McAuley, 2009; Newland, Fearing, Riley, & Neath, 2010). In one such study, Newland and colleagues (2010) found evidence that pain, fatigue, depression, sleep disturbance, and impaired cognitive function cluster in RRMS.

Symptom clusters are complex and have been studied extensively in cancer and other diseases (Miaskowski et al., 2006; Gift, Jablonski, Stommel, & Given, 2004; Bender et al., 2008; Ryan et al., 2007; McSweeney, Cleves, Lefler, & Yang, 2007). Although each symptom may not share a cause and symptoms may have a variety of causes, they can occur in a recurring grouping or be strongly related to another. A symptom cluster is three or more symptoms related to each other in time and may reveal certain clinical characteristics, such as co-morbidities (Dodd et al., 2001). The important element that a symptom cluster paradigm brings to clinical research is the ability to explore the influence of one symptom on another or influences from the simultaneous appearance of the set. The possibility exists for defining the role of side effects of one symptom management strategy in generating new symptoms or exacerbating other symptoms, and the potential for identifying common causal mechanisms such that treating the mechanism may relieve or prevent several different symptoms. However, few studies have been published to date on symptom clusters in MS (Motl & McAuley, 2009; Newland et al., 2010.). In one such study, Newland and colleagues (2010) found a cluster of pain, fatigue, depression, sleep disturbance, and impaired cognitive function in women with RRMS.

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Most of the research on MS symptoms has been quantitative and very little (Courts, Buchanan, & Werstlein, 2004; Douglas, Windsor, & Wolin, 2008) evidence exists utilizing qualitative methods such as focus groups to obtain a rich and complete description of symptoms experienced by persons with MS in their own words. In addition, the use of qualitative methodologies to draw out the full experience of MS symptoms including co-occurring symptoms has been rare.

Purpose

Our purpose was to fully characterize symptoms experienced by persons with RRMS and to do so in patients' own words. Symptom checklists for MS have been widely used in the literature (Gulick, 1989). We used focus groups to elicit patient descriptions of symptoms over time, and whether these were new or different from previously used symptom checklists. Objectives of the study included: 1) capturing the frequency of mentioned symptoms, 2) identifying symptoms not included in existing checklists and 3) characterizing combinations of symptoms to add to a symptom checklist.

Methods

Design

A series of three focus groups were conducted to elicit the words of the subjects with RRMS. Focus groups are well suited for research intending to capture the richness of life experiences as described by subjects. One advantage of the focus group as a method is that it encourages sharing of individual stories that lead to participants describing, confirming and embellishing their experience with symptoms. The give and take of the discussion draws participants to articulate experiences or to validate those of others in ways that may not occur in a one-on-one interview or a questionnaire. The informed facilitator can reflect descriptions back or ask for clarification that can draw even reticent participants to describe their symptoms. The primary researcher served as the group facilitator and her extensive clinical knowledge of the MS experience provided insight and facilitated building rapport within the focus groups.

Sample

The three focus groups included subjects with RRMS from the community. A convenience sample of focus group participants (N = 16) was recruited from MS clinics in the Midwest during routine appointments and from a local MS society's list serve. The inclusion criteria were a definite diagnosis of RRMS, being over age 18 and willing to discuss symptoms in a focus group. The sample included women (n= 12) and men (n= 4) who ranged from ages 18 to 70. We chose RRMS subtype since it is the more prevalent subtype and produces a more homogeneous sample.

Procedure

Approval was obtained from all affiliated universities' institutional review boards (IRBs) before beginning the study. The primary investigator (PI), first author, obtained permission and visited each clinic to invite persons with RRMS to participate in the focus groups. After consent, each participant completed a brief demographic form. Interested participants shared contact information for reminder calls and for mailing. The location of each focus group was a medical center familiar to the participants. Each focus group was approximately 90 minutes in duration. The first author facilitated the discussion using predetermined questions (Figure 1) and follow up open-ended probes, such as: tell me more, can you describe that, which came first, did (symptoms) occur together? No specific symptoms were asked in the interview to allow for broad discussion. Content was taped and transcribed verbatim.

immediately after the group's discussion. Analysis of the focus group transcripts, described in the next section, occurred after each focus group. Only three focus groups were conducted as saturation was achieved with the analysis of the third focus group's transcript. Each participant received \$25 at the conclusion of the focus group.

Analysis

The audio-recorded focus group interviews were transcribed verbatim, processed and coded with the help of qualitative computer software Atlas.ti (Berlin, Germany, version 6.215). Transcription notes provided data on the context. These were analyzed and checked for accuracy. Data analyses followed the method of Krippendorff (2004) and included reading each transcript for initial content, coding each sentence and tagging each mention of a symptom. The Frequency of mentioned symptoms by each participant was noted, as was the co-occurrence of symptoms (Krippendorff, 2004). Symptoms were grouped together as mentioned and used with summative content analysis (Potter, & Levine-Donnerstein, 1999) and if mentioned in a different context, these were coded separately. We compared and contrasted coding and symptoms identified across the focus groups to validate the accuracy of identified patterns (Sandelowski, 1995).

Results

Sample

The 16 persons with RRMS participated in three separate focus groups (n = 4, n = 8, n = 4). The majority of participants were female (n = 12, 75 %), and white (n = 12, 75%) with the remainder African American. Ages of the participants ranged from 25 to 58 years with a mean age of 42 years. Most of the participants reported use of disease modifying drugs (DMT) (n = 15, 93.8%). A majority self-reported having had magnetic resonance imaging (n = 10, 62.5%), and experiencing at least one relapse (n = 11, 68.8%).

Symptom Expression

The voicing of symptoms in the focus groups had a distinct co-occurring pattern in contrast to single symptom reports found in the literature. Focus group participants were asked to describe whether symptoms co-occur or happen together (Figure 1). The newly described single and co-occurring symptoms mentioned were reflected across groups and relate to the common symptoms of MS (Tables 1 and 2). However, the most notable results here are the various expressions and patterns of symptom co-occurrence. During the group discussion, participants often described a common symptom (Table 1) as occurring in isolation and co-occurring with other symptoms, regardless of participant background. Among these, were unique ways of explicitly describing pain as “pulling” or “feeling of a glove-like sensation” even when resting or having nothing on their skin. A common pattern mentioned was feeling a “tight glove”, or a “band like sensation” or “hug” feeling that cannot be removed. Another problem communicated was because pain is not something others “see”, participants felt invalidated by those around them as if “no one gets it”. Another highlighted symptom expressed was “scratching” until “skin was raw”. Even though less prominent than other single symptoms, the participant was very unaware of the “need to scratch” at the time. Men in the focus groups mentioned sexual difficulties; this negatively influenced their self-esteem and relationships with partners.

Fatigue, cognitive loss, and heat intolerance. A common expressed symptom was fatigue, which seemed to be related to cognitive loss, heat intolerance, and vision loss. A majority of participants throughout the period since their diagnosis experienced fatigue. There were new expressions of fatigue mentioned in terms such as feeling “drained” or “wiped out”. Commonly mentioned was feeling “shut down”. However, the participants all agreed there

was no way of knowing when fatigue would hit, and that they would “*push through it*” in order to accomplish what they wanted to do. For example, one participant stated,

When I’m tired, I can’t eat, because I can go all day and sleep...I get the salt free crackers. I’ll get in the bed, and I’ll muster up energy to go get that, put it in the bed with me and this is how tired I am. I’ll get a cracker, put it in my mouth, I’ll go to sleep and when I wake up the cracker’s still there, and I’ll chew a little, go back to sleep, wake up, chew a little, the cracker’s been in my mouth the whole time I’m sleeping, this is how I eat, because I’m just that tired.

One man described a situation where he could not complete the simple task of holding his child and stated,

“Well what identified it [MS] was my wife and I, we had a daughter... just holding her, my arms would, it would be like 10 minutes and I would be like here, you hold her because the weakness in my legs from holding her and standing”.

Cognitive symptoms including memory disruptions were described in many ways. Problems with cognitive function or memory problems emerged as a frequent symptom by several participants. This was associated with the vicious cycle of concentration, memory, and speaking. Most would articulate that there was the problem of being in the middle of a sentence; then forgetting a word. Likewise, others would say that they “*totally forgot what they were going to say*.” As one woman explained,

I have to tell you that the cognitive is just the most distressing... whole cognitive thing I didn’t even realize...so that I could do the job, because I was having to constantly call back, and that’s when I realized that I had a cognitive problem and my new employer was getting frustrated and I was getting really frustrated and I thought this is it, you can’t do things that you used to do.

These two symptoms together (fatigue and cognitive loss) especially added to the frustration of the participants. A typical description was “*cannot separate forgetting things and fatigue*.” Another common co-occurring pattern of symptoms was fatigue with heat intolerance. Fatigue would get worse if they became hot or drank something hot. As described by one participant,

And it happens more in the summer, in the heat, but I still get it now and a lot of it, if I don’t get my sleep I’m just blah.

In most, fatigue and heat intolerance affected their usual routine housework; often leading to compounded symptoms.

Balance problems, heaviness, vision loss, and heat intolerance. The novel description of these experiences “*standing up and falling right down to the ground*”. Many mentioned walking into people or objects, such as walls, as if being intoxicated. The following example was given,

After a while, some of my neighbors kind of said they thought I was drunk, but who can be drunk at 6:00 in the morning when you get off work... But you don’t realize you’re wobbling and walking crooked, but you know... I have the foot drop, you don’t realize it dragging until it makes you fall down... I stumble every morning when I get out of bed’

The heaviness persisted with balance problems. All groups provided feedback on statements of “*feeling off balance*”. A few participants shared feelings of “*being upside down*” and “*off balance*”. Participants described a myriad of ways that heaviness and loss of vision left an impression on their lives. The new way of describing heaviness (Table 2) more explicitly

describes the weakness mentioned by MS patients. When a few participants had a “heavy feeling”, they also experienced vision loss and balance problems. One participant reported,

“Like the heaviness in my legs is like little bitty cement bags on my ankles, and it’s always loss of vision or blurred vision in my right eye, always together like a couple”

Although participants understood heat intolerance was a common problem in MS, most found it disturbing when it was connected with blurred or loss of vision. Some related the experience as total blindness, shadowing, shading on one side of the eye, and double vision. A few mentioned uncomfortable eye movement when overheated. Most stated these symptoms impacted ability to do routine daily tasks. When asked what occurred since diagnosis, they stated that some symptoms come and go, while others persist.

Discussion

Together, these findings suggest the importance of capturing single and co-occurring symptoms in participants’ own words. Our study validates the use of focus groups as a methodology to explore the experience of symptoms. These findings provide evidence of, and, offer insight into the pattern and co-occurrence of symptoms experienced by persons with RRMS. Co-occurring symptoms do exist and are recognized very clearly by focus group participants (Table 2). In addition, several symptoms seldom included in the published literature were uncovered such as heat intolerance, itching, headache, band like sensations, and more detailed descriptions in the mention of pain.

The unique way symptoms were described in detail (Table 1) may indicate that dealing with single symptoms and co-occurring symptoms (Table 2) is particularly problematic for MS patients. Participants clearly highlighted how the manifestation of “*symptoms that come and go unexpectedly*” leads to disruption of their daily lives and functional ability. This may reflect their difficulty with “*acceptance*” that certain symptoms are an expectation, and participants’ perception that healthcare professionals do not fully appreciate the impact of their symptoms. It also is conceivable that the single symptoms reported, which are similar to those listed in existing literature (Kister, Caminero, Monteith, Soliman, Bacon et al., 2010; Marino, 2009), may be a direct consequence of gaps in comprehensive assessment during routine health care visits. The assessment tools employed may not include these symptoms at all or include them only in a group of symptoms rather than alone.

The participants’ emphasis on the co-occurring symptoms of fatigue and loss of cognition has not been addressed in the current literature (Glanz, Healy, Rintell, Jaffin, Bakshi, & Weiner, 2010; Kinsinger, Lattie, & Mohr, 2010). Many discussed situations when they were unable to remember things, which would inhibit day-to-day interactions, and that this was closely linked to unpredictable episodes of extreme fatigue. Over time, a downward spiral may occur in which they find themselves unable to acquire information, communicate effectively, problem solve, or perform tasks of daily living. While these are related symptoms, each should be assessed separately in the clinical setting to allow for individualized management strategies. Further work should identify the possible timing of these symptoms in the progression of the disease or in the course of the day.

Heat intolerance and it’s related consequences occurred frequently as a symptom, as in other studies (Flensner, Ek, Söderhamn, & Landtblom, 2011). Participants often identified heat intolerance as occurring with a sense of heaviness and loss of vision (Nybo & Nielsen, 2001). The very nature of the effect of ambient heat on neurological function is a result of slowed nerve conduction and conduction block and is not necessarily a result of environmental stimuli (Baker, 2002; Flensner et al., 2011; Marino, 2009). Persons with MS

can have an inordinate response to a warm environment, humidity, exercise, or hot food or beverages. When paired with fatigue and weakness, significant interference with family life may result. When heat intolerance occurs with vision loss, participants express how acutely aware they are of how safety issues can emerge. This can result in avoidance of activities and subsequent feelings of not being loved, loneliness, and isolation.

Limitations and Strengths

The study design includes the following limitations. Even though our focus group participants were recruited from a variety of settings some patients with RRMS may not feel comfortable discussing symptoms in a group and so symptoms would not be represented. The focus groups were made up largely of white women; however, this reflects the MS population as a whole and of the clinics from which participants were recruited. A major strength of our study was the diverse age group of the participants. Likewise, the high percentage of agreement in coding and interpretation between the first and second author supports the consistency of the content analysis.

Nursing Implications

Given the myriad of symptoms, a multidisciplinary approach to care is warranted to effectively assist those living with MS. Many of the reported symptoms are not obvious to others but were articulated as more bothersome or interrelated by our study participants. We indicate the importance of identifying symptoms, not only individually, but as they co-occur to better manage care of patients with MS and to assure a sense that their experience is understood and appreciated. Healthcare professionals need to assess for gaps in symptom management in every encounter. Patients should be encouraged to give detailed descriptions of their symptoms and their interrelationship to ascertain the full effect on their daily lives and relationships. Healthcare professionals need to refer MS patients for resources and restorative interventions. Education is needed that is directed to safety, maintenance of current level of function, full disclosure of stressors, and coping mechanisms. Patients could also be assisted to identify the triggers and cues that bring on debilitating symptoms so that they can anticipate and perhaps avoid unsafe or otherwise undesirable consequences.

These findings emphasize the challenges of developing a measure of symptom occurrence in persons with MS. A more comprehensive clinical tool is needed. One plausible guideline may be to question patients at each visit about the different characteristics of their most common symptoms and to phrase the questions using various commonly used descriptors.

Our findings emphasize the need to further investigate heat intolerance, fatigue, and cognitive and vision loss and their patterns of occurrence and co-occurrence. Prompt assessment of this set of symptoms may allow anticipation of additional symptoms or exacerbation of MS and earlier or more appropriate interventions. Future directions for research include identifying management techniques and interventions that are indicated by co-occurring symptoms. Replication of this study in a larger sample, with more diverse ethnic groups, in other geographic areas (to evaluate extremes in hot and cold) would be beneficial.

Since sexual problems were only identified in men, there is a need to validate this finding in a larger group of men with MS and also investigate this aspect more with women. Women may be more reticent about discussing this issue. In our focus groups the women did not confirm, deny, or discuss sexual issues when presented by the male participants. For the men, it was a very distressing symptom to deal with and very frustrating since there was such a lack of response from the female members of the group.

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The following are examples:

1. Please tell me what kinds of things have happened to you since you were diagnosed with MS.
2. What has happened with your symptoms since your diagnosis with MS
3. What symptoms have you experienced with MS?
4. What symptoms have had the greatest impact on you?
5. In what order did your symptoms appear? Did they come and go? What if any symptoms did you have that occurred at the same time? For example, when you had pain did you have other symptoms?

Figure 1.
Sample Interview/Focus Group Stems and Probes

Table 1

Summary of Newly Described Symptoms Voiced by Patients with Relapsing –Remitting Multiple Sclerosis (RRMS)

Band like sensation in the leg	N = 2	Pain: described as knifelike	N= 1
Band like sensation in the torso	N=2	Pain: described as pulling sensation	N=2
Feeling of wearing a “glove”	N=1	Pain: described as prickly/nerve sensation	N= 3
Difficulty concentrating	N= 5	Twitching	N =4
Sexual Problems	N=2	Foot drop	N =5
Heat intolerance	N =8	Headache	N = 6
Itching	N =1		

Table 2

Summary of Identified Co occurring Symptoms in Patients with Relapsing-Remitting Multiple Sclerosis (RRMS)

Fatigue and loss of cognition	N=4
Heat intolerance and vision loss	N=3
Heat intolerance and fatigue	N=3
Feeling of heaviness and vision loss	N=2