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Multiple Sclerosis and Fatigue: Understanding the Patient's Needs

Karon F. Cook, PhD[a], **Alyssa M. Bamer, MPH**[b], **Toni S. Roddey, PhD**[c], **George Kraft, MD**[b], **Jiseon Kim, PhD**[b], and **Dagmar Amtmann, PhD**[b]

[a]Department of Medical Social Sciences, Northwestern University, Chicago, IL

[b]Department of Rehabilitation Medicine, University of Washington, Seattle, Washington

[c]School of Physical Therapy, Texas Woman's University, Houston, Texas

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INTRODUCTION

Fatigue is among the most common and debilitating symptoms of Multiple Sclerosis (MS), affecting approximately 80% of persons who have the disease.[1–4] In one study, 69% considered fatigue their worst symptom.[5] Fatigue in MS may directly impact participation in important roles such as employment[6,7] and can profoundly magnify other MS symptoms.[8]

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[a]Corresponding Author: Karon F. Cook, PhD, Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, Faculty, Department of Psychology, 625 N. Michigan Ave., Suite 2700, Chicago, IL. 60611, Phone: 713.291.3918, karon.cook@northwestern.edu.
Co-Authors:
[b]Alyssa M. Bamer, MPH
[c]Toni S. Roddey, PT, PhD, OCS, FAAOMPT, School of Physical Therapy, College of Health Sciences, Texas Woman's University-Houston Center, 6700 Fannin Street, Houston, TX 77030, Phone: 713.794.2067, TRoddey@twu.edu
[b]George H. Kraft, M.D., M.S., Alvord Professor of MS Research, Emeritus Professor, Rehabilitation Medicine and Neurology, Director, MSRRTC, University of Washington, Dept. Rehab. Med., 1959 NE Pacific Street, Box 356490, Seattle, WA 98195-6490, Phone: (206) 543-7272, ghkraft@uw.edu
[b]Jiseon Kim, PhD
[b]Dagmar Amtmann, PhD, Department of Rehabilitation Medicine, University of Washington, Faculty, School of Medicine, Box 354237, Seattle, WA 98195-4237, Phone: 206.543.4741, dagmara@uw.edu

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Fatigue is a subjective experience, and currently there is no laboratory test to measure it. Therefore, the assessment of fatigue typically is accomplished through self-report. In recent years standardized self-report measures have been developed using an item banking approach.[9] Recently, as part of NIH's Patient Reported Outcome Measurement Information System (PROMIS), a bank of items was developed for measuring self-reported fatigue.[10] In the PROMIS domain framework fatigue is defined as " an overwhelming, debilitating, and sustained sense of exhaustion that decreases one's ability to carry out daily activities, including the ability to work effectively and to function at one's usual level in family or social roles".[11] (p. 1318)

This study had two purposes. The first was to assess, from the perspective of individuals living with MS, the relevance of a subset of items from the PROMIS fatigue item bank. The second purpose was to identify additional aspects of fatigue that individuals with MS believed were important for clinicians to ask about their fatigue experience.

(TAGS: fatigue, quality of life, Patient Reported Outcome Measurement Information System (PROMIS))

METHODS

Participants

Institutional review board approval was obtained for the study from the appropriate institutions and all rights of human subjects were protected in this research. Participants were recruited through a website and print advertisements as well as from a disability registry maintained at the University of Washington, Seattle (UW). Individuals in the registry who had MS were sent an invitation letter followed by a phone call to assess their interest in participation.

Procedures

To evaluate the level of fatigue in our sample, we began the survey with the item, "To what degree have you experienced fatigue."[12] The item was scored on a 0–10 numerical rating scale where 0 = "not at all" and 10 = "a great deal".

Item Rankings—We designed a sorting and ranking procedure to quantify, from the perspective of persons with MS, the relevance of items in the PROMIS fatigue bank. The full item bank consists of 95 items, and we judged this to be too many for individuals to meaningfully rank. Study investigators reduced the items to 20 in a series of successive steps described in detail elsewhere.[13] To summarize, we reduced the item pool to 44 items by eliminating items with duplicate content. These 44 items were ranked by 27 Physical Therapists, 7 Medical Doctors, and 3 Occupational Therapists. Based on their ratings and on cumulative coverage of content, the item pool was further reduced to the 20 items presented to participants.

The selected items were printed onto 20, 2" × 3.5" paper note cards and mailed to participants along with written instructions for the ranking procedure. Participants first responded to the question, "To what degree have you experienced fatigue?" Responses ranged from '0' (not at all) to '10' (a great deal). Next participants identified and recorded the three items of the 20 that they considered the most relevant to their fatigue. Instructions stated, "If your doctor were to ask you **three (only 3)** questions about your fatigue, what 3 questions would give your doctor the best description of your fatigue?" Next participants selected the item from those remaining that they would want asked if they could add just one more question. This procedure was repeated until participants had chosen a total of 10 items.

The three items selected as giving “the best description” were assigned a ranking of “8”. The fourth item selected was assigned a ranking of “7”, and so on through the tenth item that was assigned a ranking of “1”. Thus, higher values indicated stronger preference.

Open Ended Responses—After identifying and ranking their top 10 items, participants were asked, “Are there other questions (ones not printed on the cards) that you think are needed for a good summary of your fatigue?” Space was provided for participants to write in responses.

Analysis

Item Rankings—The item rankings provided by participants were ordinal-level, not interval-level, data; therefore, the appropriate average of these ranks is the median. However, because only 10 items per person received a rank (all others were scored as zero), the median rankings for most items was zero. To better discriminate among item ranks, we calculated the arithmetic mean rank across raters, referred to hereafter as the “relevance index” (RI). We note that this index provides relative (not equal-interval-level) information about the strength of participant preferences for one item over another.

Open Ended Responses—Responses to the open ended questions were categorized according to recurring themes. Two of the study investigators (Cook and Bamer) independently reviewed participant responses and developed categories they thought adequately summarized the content of responses. The investigators then met and came to agreement on names and number of organizing categories. Each investigator again reviewed responses and categorized them into the agreed upon categories. After making classifications independently, they met and compared results, resolving discrepancies by consensus.

(TAGS: Outcomes Assessment, Psychometrics)

RESULTS

Participants

Of 31 invited individuals with MS from the UW registry, 21 (68%) agreed to participate and completed the sorting procedure. Forty-one additional subjects saw a study advertisement or heard about the study from someone else and contacted the researchers directly. Of these 41, 25 (61%) subsequently completed the sorting procedure, for a grand total of 46 participants with MS. Characteristics of the participants are reported in Table 1.

Item Rankings

RI values were calculated for each of the 20 items reviewed by participants and are in Table 2. As the table reports, the two items with the highest rankings were, “How often did you feel tired even when you hadn’t done anything,” and, “How often did you have to push yourself to get things done because of your fatigue?” Other highly ranked items had to do with feeling tired and fatigue’s impact on “finishing things”, “physical function”, and “thinking clearly”.

Four of the six lowest ranked items had to do with participation (i.e., socializing with family, recreational activities, leaving the house, and participating in social activities). The other two low ranked items asked about the impact of fatigue on bathing/ showering and about frequency of experiencing “extreme exhaustion.”

Open Ended Responses

Of the 46 participants, 30 made a total of 68 item suggestions in response to the query, “What other information should be asked in addition to the top ten questions you selected.” After reviewing the content of open ended responses, study investigators identified seven recurring themes and two comments that each formed its own category. One of these was the suggestion to ask “questions relating to sexual relations.” Another recommended that the opportunity be given “to comment with greater detail.” The complete results are reported in Table 3. Many of the participant suggestions were consistent with content typically represented in standardized fatigue measures. Of the 68 suggestions, 13 pertained to impact of fatigue on activities of daily living (ADLs) and instrument ADLs (IADLs), 5 pertained to cognitive impact, and 10 had to do with the emotional impact of fatigue.

A substantial number of suggestions, however, referenced content not typically covered in standardized fatigue measures. Twelve comments pertained to fatigue triggers (e.g., “How does the heat affect your fatigue?”). Eleven suggested adding questions that had to do with duration, frequency, or other temporal aspects of fatigue (e.g., “What time of day are you most fatigued?”). Ten comments pertained to the specifics of how individuals coped with their fatigue (e.g., “How often do you plan a nap into your day in order to have the energy to do an activity later in the day?”). Another area of concern for participants was the distinction between their fatigue and other symptoms and functions (i.e., pain, physical function, bladder, vision, depression). For example, one participant suggested the item, “Do you feel you can’t get out of the house due to physical fatigue or is it due to the depressive elements of the disease?

DISCUSSION

We documented the relevance of a subset of items of the PROMIS Fatigue item bank in a convenience sample of individuals with MS and identified the items participants believed had the greatest relevance to their experience of fatigue. In previous work, we used these rankings and similar rankings by clinicians to develop the PROMIS FatigueMS, an 8-item short form derived from the PROMIS fatigue item bank.[13] However, it was clear from the input of persons with MS that the content covered by this subset of items did not exhaust what they believed clinicians should ask them in trying to understand their fatigue. When asked to suggest additional items that would give their healthcare provider the “best description” of their fatigue, participants included items about coping strategies, distinguishing fatigue from other experiences, fatigue triggers, and temporal aspects of fatigue. These suggestions were consistent with the self-management challenges of living with MS and the documented impact of fatigue on quality of life.[3,4] Participant comments demonstrated their desire to discuss such issues with the clinicians who treat them.

This finding has implications for the use of self-report measures in clinical practice. Recent studies have documented both the feasibility and the advantages of incorporating patient reported outcome measures into clinical practice.[14,15] But these studies do not address the need to assess concerns that cannot effectively be evaluated using standardized measures. No self-report measure can gather the detailed and personally relevant information that a skilled clinician can elicit. Nor can a self-report measure replace the trust built when there is effective communication between a healthcare provider and a patient. It is possible, however, that standardized measures may “open the door” for such communication. In one randomized controlled trial, the use of self-report measures along with graphical feedback significantly increased the frequency with which health related quality of life issues were discussed between doctors and patients in a clinical setting.[16]

This study had a number of limitations. The convenience sample used was relatively small (N=46) and was taken from a single geographic area. Therefore, the results may not generalize to other individuals with MS. In addition, it is well known that there are many confounders of MS fatigue, such as depression, pain, and sleep disturbances. These were not addressed in the current study.

CONCLUSION

Future studies should evaluate the generalizability of our findings. Future measurement development efforts should examine both the challenges of incorporating standardized assessments of fatigue into clinical practice and the role of these assessments in facilitating communication between clinical providers and individuals with MS.

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Key Points

- Fatigue substantially impacts quality of life for persons with Multiple Sclerosis (MS).
- A sample of individuals living with MS ranked a subset of self-report items with respect to their relevance in measuring fatigue in MS. The most highly ranked items were, “How often did you feel tired even when you haven’t done anything” and, “How often did you have to push yourself to get things done because of your fatigue?”
- No self-report measure can gather the detailed and personally relevant information that a skilled clinician can elicit. It is possible, however, that standardized measures may “open the door” for such communication.

Table 1

Participant Demographics and 0 to 10 Fatigue Ratings

Demographics	
Age (years)	Mean = 54.1, SD = 9.3
Disease Duration (years)	Mean = 14.1, SD = 8.2
Female	N= 37 (80.4%)
Fatigue (0–10 scale)	
None (0)	N = 2 (4.3%)
Mild (1)	N = 0 (0%)
Moderate (2–4)	N = 5 (10.8%)
Severe (5–10)	N = 39 (84.8%)

Table 2

Relevance Index values (mean participant ranking) for items from the Patient Reported Outcomes Information System (PROMIS) Fatigue Item Bank

PROMIS Item Name	**Item Content**	**Relevance Index**
FATEXP6	How often did you feel tired even when you hadn't done anything?	4.39
FATIMP3	How often did you have to push yourself to get things done because of your fatigue?	4.37
FATIMP16	How often did you have trouble finishing things because of your fatigue?	3.82
FATIMP49	To what degree did your fatigue interfere with your physical functioning?	3.67
FATEXP48	How often did you find yourself getting tired easily?	3.37
FATIMP30	How often were you too tired to think clearly?	3.26
FATIMP33	How often did your fatigue limit you at work (include work at home)?	3.17
FATEXP7	How often did you feel your fatigue was beyond your control?	2.76
FATIMP14	How often did your fatigue make it difficult to organize your thoughts when doing things at work (include work at home)?	2.63
FATEXP26	How often were you too tired to enjoy life?	2.43
FATIMP17	How often did your fatigue make it difficult to make decisions?	2.13
FATEXP34	How tired did you feel on average?	2.09
FATIMP9	How often did you fatigue make it difficult to plan activities ahead of time?	2.09
FATEXP21	How fatigued were you when your fatigue was at its worst?	2.07
FATIMP4	How often did your fatigue interfere with your social activities?	1.93
FATEXP5	How often did you experience extreme exhaustion?	1.93
FATIMP29	How often were you too tired to leave the house?	1.91
FATIMP21	How often were you too tired to take a bath or shower?	1.34
FATIMP15	How often did your fatigue interfere with your ability to engage in recreational activities?	1.15
FATIMP26	How often were you too tired to socialize with your family?	0.67

Table 3

Participant Comments Classified by Category

Item/Statement	Category
Because of your fatigue, do you find your personal hygiene sliding?	*ADL/IADL Impact
Because of your fatigue, do you find yourself compromising (letting things slide)?	ADL/IADL Impact
Because of your fatigue, do you find yourself skipping meals or eating late or making smaller meals?	ADL/IADL Impact
Do you fall asleep while doing things you want to do like watching a good movie, being on computer or reading a book?	ADL/IADL Impact
Does fatigue affect your handwriting? Computer skills?	ADL/IADL Impact
After a shower/bath and getting dressed, do you feel you expended most of your energy?	ADL/IADL Impact
Ask questions regarding specific activities of daily living that are being affected by fatigue; dressing, meal preparation, organization within home, paying bills on time, making and keeping appointments	ADL/IADL Impact
Ask questions regarding specific activities of daily living that are being affected by fatigue; dressing, meal preparation, organization within home, paying bills on time, making and keeping appointments	ADL/IADL Impact
Did you ever get part way through a project and you were alone and thought “oh oh” I bit off more than I can chew! Now what do I do?!	ADL/IADL Impact
Does your brain or your body parts tell you “when is enough”. Sometimes you try something and right away or part way your brain says oh! Oh!	ADL/IADL Impact
Getting dressed, put on makeup, take care of pets, fixing something healthy for meals, especially living alone.	ADL/IADL Impact
How often are you too tired to plan/cook a meal at the end of the day?	ADL/IADL Impact
How often do you get “fast food” because you are too tired to cook/plan a meal	ADL/IADL Impact
How often do you not have the energy for “unplanned” activities?	ADL/IADL Impact
Because of your fatigue, did you come to realize you made improper decisions?	Cognitive
How does using your cognitive drain you?	Cognitive
Did you feel like fatigue affected your memory?	Cognitive
Do you feel at times you are in a mental fog?	Cognitive
Do you have difficulty saying what you mean?	Cognitive
Does a nap at certain times of day help manage fatigue?	Coping
How often do stimulants help	Coping
How often do you take “energy boosters” (stimulants, caffeinated beverages, chocolate, medication) to decrease your fatigue?	Coping
Realizing your fatigue, do you think you could have done things differently?	Coping
What do you do to stabilize situations?	Coping
How do I recover?	Coping
How often do you plan a nap into your day in order to have the energy to do an activity later in the day?	Coping
Need to ask demographic questions about effect of medication on fatigue	Coping
What did you do to lessen your fatigue?	Coping
What do you do when fatigued?	Coping
At what point in a typical day do you “run out of gas?”	Temporal
How fatigued do you feel upon waking in the morning?	Temporal
How often after a busy active day are you so tired that the following day you spend resting?	Temporal
What time of day are you most fatigued?	Temporal
Do the change of seasons influence your fatigue?	Temporal

Item/Statement	**Category**
How long do bouts of fatigue last?	Temporal
How long to recover?	Temporal
Is there a time of day that you experience fatigue regularly?	Temporal
Perhaps inquiring about a person’s fatigue and how it progresses (or doesn’t) throughout a typical day	Temporal
What/when are your best times during a typical day?	Temporal
Do you ever feel like life is going by and think what’s the point?	Emotional Impact
Does your fatigue affect your happiness?	Emotional Impact
Does your fatigue affect your overall well being and satisfaction with life?	Emotional Impact
How does it affect the quality of life for you?	Emotional Impact
How often does fatigue cause short temper?	Emotional Impact
How often does fatigue decrease patience with yourself?	Emotional Impact
How often do you just not care about people or getting things done?	Emotional Impact
How often do you reflect back to what you used to accomplish in a day?	Emotional Impact
Questions regarding fatigue and mood	Emotional Impact
Do you feel like your fatigue is a problem?	Emotional Impact
Does pain interfere with fatigue?	Symptom Interaction
How often do you think that if you could eliminate or reduce your pain you would have less fatigue?	Symptom Interaction
How often does fatigue interfere with physical function?	Symptom Interaction
Do you feel you can’t get out of the house due to physical fatigue or is it due to the depressive elements of the disease?	Symptom Interaction
How fatigue effects bladder and eye sight control	Symptom Interaction
Have you noticed any patterns/triggers for your fatigue?	Triggers
How does the heat affect your cognitive?	Triggers
How does the heat affect your fatigue?	Triggers
How often did background noise affect your fatigue	Triggers
How often did stress affect your fatigue	Triggers
What fatigues you more – walking or things done with your hands and arms?	Triggers
What has changed in your life?	Triggers
Have you had any other illness in the past 7 days?	Triggers
How often did heat affect your fatigue	Triggers
Is your fatigue triggered at certain times of day?	Triggers
What are my daily activities and which are most tiring	Triggers
What has been going on in family life, work life, social life in the past 7 days?	Triggers
I think there needs to be an opportunity to comment with greater detail.	General Comment
Questions relating to sexual relations	Impact on Sex

Note: ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living