Unmet Service Needs in MS: A Report on Focus Groups
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INTRODUCTION
The Pacific Northwest has a high prevalence of MS. The Greater Northwest Chapter of the National Multiple Sclerosis Society serves over 12,000 people with multiple sclerosis (MS) in Alaska, Montana and Washington. Focus groups of the members of the Greater Northwest Chapter were conducted to explore unmet needs and quality of life issues.

Focus groups allow for a discussion of important topics where participants inform each other's contribution and stimulate discussion. Asking about what is important to individuals living with MS was the first step in designing a needs assessment survey that reflects the topics that people living with MS and caregivers of people with MS consider important.

PURPOSE
To explore issues around living with MS and caring for an individual living with MS in order to inform the content of a needs assessment survey.

METHODS
Participants with MS were recruited by referral through the National MS Society or through contact with an adult day center. Caregivers of individuals with MS were recruited through the National MS Society as well and through a regularly-scheduled MS caregiver support group. Participants included 6 people with MS utilizing an adult day center, 30 community-dwelling adults with MS, and 10 caregivers of people with MS. Participants completed questionnaires assessing basic demographic information. Focus groups were conducted in-person or over the phone by a University of Washington faculty member trained and experienced in facilitation. The facilitator asked open-ended questions to simulate discussion.

ANALYSIS
Discussion was transcribed and recorded in real-time. Transcripts were coded in Atlas Ti and analyzed using a phenomenological approach.

Table 1. Focus Group Participant Characteristics

<table>
<thead>
<tr>
<th>Variable</th>
<th>People with MS Mean (Range)</th>
<th>Caregivers Mean (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td>51 (23 – 71)</td>
<td>61.3 (39 – 68)</td>
</tr>
<tr>
<td>Years Since Diagnosis</td>
<td>13.3 (1 – 31)</td>
<td>13.2 (4 – 34)</td>
</tr>
<tr>
<td>Gender</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>MS Type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relapsing-Remitting</td>
<td>15 (48.4%)</td>
<td>2 (28.6%)*</td>
</tr>
<tr>
<td>Secondary Progressive</td>
<td>9 (29%)</td>
<td>2 (28.6%)*</td>
</tr>
<tr>
<td>Primary Progressive</td>
<td>4 (12.9%)</td>
<td>3 (42.9%)*</td>
</tr>
<tr>
<td>Progressive Relapsing</td>
<td>3 (9.7%)</td>
<td>0*</td>
</tr>
<tr>
<td>Female</td>
<td>28 (80%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Some college or higher</td>
<td>27 (77.1%)</td>
<td>9 (90%)</td>
</tr>
<tr>
<td>Married or in a Relationship</td>
<td>20 (57.1%)</td>
<td>10 (100%)</td>
</tr>
</tbody>
</table>

Three Themes Emerged

(1) Access to community and services
- "...it's hard to maintain a home on Social Security... my problems are mainly [financial]."
- "We have one neurologist in the valley area, and then we have access, of course, to all the neurologists in Anchorage, but they're an hour away."
- "The insurance issue is huge."
- "The Access bus... was a half day ordeal."

(2) Problems associated with MS
- "There are no wheelchairs for your brain."
- "The one thing I find a lot of is fatigue... it's steadily gotten worse..."
- "I have been agonizing for the last year and a half over, oh my God, what am I going to do? Where am I going to live? This is progressing so fast."
- "Should I attend three years of Dental School you know, and I may not even be able to walk in five years?"

(3) Managing MS
- "...I lose my balance and fall... [and] I forget almost everything... I use a medical alert system and that gives me independence."
- "The community bends over backwards to help me."
- "I'm here to learn from all these people who are traveling the road with me and get some support... because the emotional adjustment has been hard."
- "I had to come to the reality that I do need to plan for [progression] because MS isn't going to go away."
- "So I just really think we can help ourselves if we get the information, get the training. There is nothing wrong with helping ourselves do this."

CONCLUSIONS
Participants in our focus groups reported that there were individual, environmental, and financial barriers to living independently and receiving medical services. They also reported that cognitive changes and increasing fatigue were particularly troublesome for them. They also discussed options that improve management of MS including technology, community support, self-management, and group support. We have concluded that consumer organizations providing services to people living with MS may tailor supports to include instruction in self-management, advocacy for accessible environments and health care, and social supports. Programming directed toward cognition and fatigue is critical. Future research is needed to identify the most effective ways that consumer organizations can provide support to people with MS.

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