Understanding the Perspective of Individuals with MS on Access to MS Medications

Access—Why it Matters

Access to affordable high quality healthcare is essential for people with MS to live their best lives. However, the escalating costs of MS medications and the barriers in accessing these medications are preventing people with MS from being able to get the treatments they need. For example, between 2004 and 2016 the average price of MS disease modifying therapies (DMTs) increased nearly 400%. The additional trend of increased out-of-pocket costs across all types of health insurance severely impacts people with MS who need an expensive medication every month for decades.

The National Multiple Sclerosis Society is committed to shining a light on the issues affecting the cost and access to the MS medications, being an agent for change and advocating for solutions to ensure that people affected by MS can live their best lives. The percutives, feedback, and cooperation of all stakeholders—pharmaceutical companies, insurance providers, healthcare providers, policy makers, people with MS and others—are needed for all of us to work together to reduce costs, simplify the system, and focus on getting people with MS the medications they need to live their best lives.

“It's hard mentally, physically and emotionally everyday with MS alone then to add the stress of the financial on top of it. And with that I still don't get the medications I need”

-Participant

Findings Summary:

- 50.2% of responses indicated little to no challenges in accessing medications.
- 47.9% of challenges were related to the current cost of treatment, insurance, or care. Additional barriers to access included:
  1. Challenges with insurance policies and coverage (20.7%)
  2. Challenges with assistance programs (8.1%)
  3. Challenges with medications (6.1%)
  4. Challenges with medication/treatment supplier (5.7%)
  5. Challenges with government options such as Medicare or Medicaid (4.5%)
- 10.6% of responses indicated that participants were currently stressed or stressed about future access of treatment.

Current Survey

- The current survey was distributed in October of 2015 and was adapted from two national surveys (Kaiser Health & Consumer Reports) to better understand how treatment cost impact the MS community.
- The survey was sent to 1.3 million constituents in the Societies' database, more than 124,000 with MS, and was completed by 8,778 participants with MS.
- Of these participants, 4,950 completed one open ended question: Tell us about any challenges you've had in getting the MS medications you need.
- Responses to the open-ended question were analyzed using a computer software program that sorts responses into various themes.

Objectives:

- The National MS Society formed an Advisory Committee on Access to MS Medications to address challenges faced by the MS community.
- Goals include: creation of recommendations intended to address ways to rally the MS movement, engagement with key stakeholders and identification of areas of collaboration where we can increase our effectiveness and creation of an environment ripe for change on cost and barriers to access.
- In addition to recommendations related to affordability, simplicity, and transparency, there is a need to ensure the voice of the MS community informs recommendations. The current examination of 4,950 open-ended responses was undertaken to elucidate the perspective of people living with MS and how access to medications impacts their lives.
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Conclusions:
A growing body of evidence indicates that early and ongoing MS treatment with a DMT is the best way to modify the disease course. The current report aimed to better understand the perspective of people with MS on access to MS medications. Findings show that a large number of respondents are unable to afford their treatments. For participants who reported being able to afford treatment, this would not have been possible without insurance and/or assistance programs. Navigating the various systems to access treatment was often highly difficult and listed as a significant life stressor. Uncertainty regarding ability to access treatment in the future had a detrimental impact on participants daily lives.

The National MS Society recognizes that something needs to be done to decrease the cost of medications and reduce the difficulty in navigating the various systems involved in getting access to treatment.

Cost Challenges
Out of the 4,950 responses, 47.9% of responses were related to the current cost of medication, insurance, or care and prohibitive income limitations.

Cost Challenges
“Don’t think it’s fair that the medication should cost so much and it’s not from something that I chose to do like smoking, illegal drugs or heavily drinking.”

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Cost Related Challenges (n=2,371)

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Cost of Treatment</td>
<td>56.3%</td>
</tr>
<tr>
<td>Cost of Coverage</td>
<td>28.8%</td>
</tr>
<tr>
<td>Cost of Care</td>
<td>5.3%</td>
</tr>
<tr>
<td>Income Limitations</td>
<td>4.4%</td>
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</tbody>
</table>

Outcomes due to Cost
When investigating how cost of medications impacts participants’ lives, three main outcomes emerged (n = 721 responses):

- **Financial Impact (39.1%)**: Participants reported work related consequences such as inability to gain employment to qualify for assistance or inability to leave/retire from current job position to maintain coverage, lifestyle changes to help afford treatment, cutting back on necessities or inability to pay bills, and negative credit impact such as declaring bankruptcy due to medical bills or paying for treatment using credit cards, savings, or retirement reserves.

- **Medical Impact (41.9%)**: Participants reported reducing or eliminating costs of medication by reducing or skipping dosage, delaying treatment, selectively using cheaper treatments regardless of effectiveness, or not getting needed medications or treatment.

- **Wellbeing and Family Impact (18.4%)**: Participants included family members being influenced by the cost of medications and cost leading to stress.

Financial Outcomes due to Cost (n=282)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work Related Consequences</td>
<td>32.3%</td>
</tr>
<tr>
<td>Negative Credit Impact</td>
<td>22.3%</td>
</tr>
<tr>
<td>Necessities and Bills</td>
<td>21.3%</td>
</tr>
<tr>
<td>Lifestyle Changes</td>
<td>18.4%</td>
</tr>
</tbody>
</table>

Medical Outcomes due to Cost (n=302)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Stopped Medications</td>
<td>58.3%</td>
</tr>
<tr>
<td>Reduced or Skipped Dosage</td>
<td>13.6%</td>
</tr>
<tr>
<td>Selective Medication Use</td>
<td>11.6%</td>
</tr>
<tr>
<td>Treatment Delay</td>
<td>10.9%</td>
</tr>
<tr>
<td>Negative Health Consequences</td>
<td>5.0%</td>
</tr>
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</table>

Wellbeing and Family Outcomes Due to Cost (n=133)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>72.2%</td>
</tr>
<tr>
<td>Family Impact</td>
<td>27.1%</td>
</tr>
</tbody>
</table>

Outcomes Due to Cost
“Don’t think it’s fair that the medication should cost so much and it’s not from something that I chose to do like smoking, illegal drugs or heavily drinking.”

“I’ve also gone without eating more than once a day or sometimes a whole day simply because I had only enough money to either pay for my medication and housing/utility bills or food.”

“I have to choose between taking MS medication or feeding, clothing and keeping a roof over my family’s head. Sadly I know and my kids know that I’m getting worse with each passing day. I get more stiff and my memory is going quickly. I keep asking for help but nobody can hear me.”

“I am a single person on disability I’ve….cut prescribed dose in half or skipped a does. I have not gotten prescriptions filled due to the expense. This is a real problem”

*Prepared by Sara Anne Tompkins, Ph.D., Madipen, LLC*
Conclusions:

A growing body of evidence indicates that early and ongoing MS treatment with a DMT is the best way to modify the disease course. The current report aimed to better understand the perspective of people with MS on access to MS medications. Findings show that a large number of respondents are unable to afford their treatments. For participants who reported being able to afford treatment, this would not have been possible without insurance and/or assistance programs. Navigating the various systems to access treatment was often highly difficult and listed as a significant life stressor. Uncertainty regarding ability to access treatment in the future had a detrimental impact on participants daily lives.

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Outcomes Due to Cost

“My health/stress level in my job has gotten to the point I shouldn’t be working 45 hours a week. I’m stuck working full time because of my MS medication.”

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