INTRODUCTION

- Multiple sclerosis (MS) is a chronic, demyelinating disease affecting an estimated 2.2 million patients worldwide.
- Specific symptoms vary widely across patients; however, in general, patients tend to accumulate considerable disability over time, which impacts their ability to work, participate in recreational activities, and engage in social interactions.
- Caregivers are an indispensable piece of the support system for patients living with MS at home, and their lives are also heavily impacted physically and emotionally. It’s not uncommon for caregivers to reduce or completely forgo employment, creating financial stress.
- Currently, there is limited research investigating how best to meet the needs of caregivers and ensure that they are optimally equipped to support patients.
- Digital resources are increasingly being recognized by patients and providers alike as valuable platforms for health interactions and, with a reported 8 billion hours/year spent online in the United States alone, they are an undeniably effective way of reaching patients wherever they are.
- Using MSConnect, a digital platform developed by Karate Health (Washington, DC, USA) that provides content and tools for the MS community, we investigated the experiences and needs of caregivers for patients with MS.

OBJECTIVES

- To better understand the challenges experienced by caregivers and the relationship between caregivers, patients with MS and the clinical team.
- To identify effective strategies to support caregivers, including shared decision-making and patient-centric programs.

METHODS

- A series of online surveys were developed for patients with MS and caregivers in the United States, and were hosted on MSCorner (Figure 1).
- Patients were recruited using digital marketing campaigns including placements on social media and search engine results.
- Surveys were completed on a volunteer basis, and participants were not compensated.
- Participants with incomplete responses were contacted via email for complete information.

RESULTS

Respondent Characteristics

- Respondents included 896 patients (134 no MS, 58 primary, 676 secondary, 14.4% progressive MS, 9% primary progressive MS, 9% progressive re-lapsing MS, 4.6% not sure, 11%) and 171 caregivers with diverse demographics from 52 states and territories (Figure 2).
- Caregivers primarily identified as a family member (typically a spouse), and professional caregivers were rarely used (Figure 3).

Commitment of Caregiving

- Caregivers indicated they were heavily involved in patients’ day-to-day routines (Figure 4), supporting an average of 4.64 tasks daily.
- One-third of caregivers reported giving ≥40 hours of care per week, for which they were largely unpaid, highlighting a considerable economic burden (Figure 5).

DISCUSSION AND RECOMMENDATIONS

- Despite their significant role in providing care to patients with MS, caregivers do not feel fully involved in care decisions or planning.
- Evidence demonstrates the considerable impact of caregiving responsibilities on the health and overall well-being of the caregivers themselves, which ultimately will have a negative impact on patients.
- Overall, findings suggest substantial value in creating caregiver-oriented content and resources that can be shared by trusted clinical providers and nonindustry organizations.
- Some considerations for caregiver-oriented materials include the following:
  - Digital content has the potential to reach a wide audience and can be readily tailored to meet a specific purpose.
  - Physician-oriented resources on caregiving may help to facilitate better integration of the caregiver into the care team and decision-making process.

CONCLUSIONS

- There is currently a lack of resources supporting the caregivers of patients with MS.
- This shortcoming can be addressed by developing caregiver-oriented content both to work in clinical practice and as thought leaders in the MS field, that can better prepare those individuals to support loved ones with MS.

DISCLOSURES

S Shankar is an employee of Genentech, Inc.
B Adelman is a co-owner of Karate Health.
A Sorathia is a co-owner of Karate Health.

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