

# Caregiving Challenges in Multiple Sclerosis and Alzheimer's Disease: Results from a Caregiver Survey Study in Two Virtual Communities

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# Background, Objectives, and Methods

## Background:

- Being a caregiver for a family member with a chronic neurological disease can be a fulfilling but often challenging role.
- Information and support from healthcare providers (HCPs) and other sources can help ease these challenges, but these resources may not always be available or offered to caregivers.
- Two national nonprofits, Accelerated Cure Project for MS (ACP) and UsAgainstAlzheimer's, have teamed up to learn about and address caregiver burdens in multiple sclerosis (MS) and Alzheimer's disease (AD).

## Objectives:

- The objective of this study was to survey caregivers for people diagnosed with MS and/or AD about key stressors, access to caregiving resources, and interactions with healthcare providers.

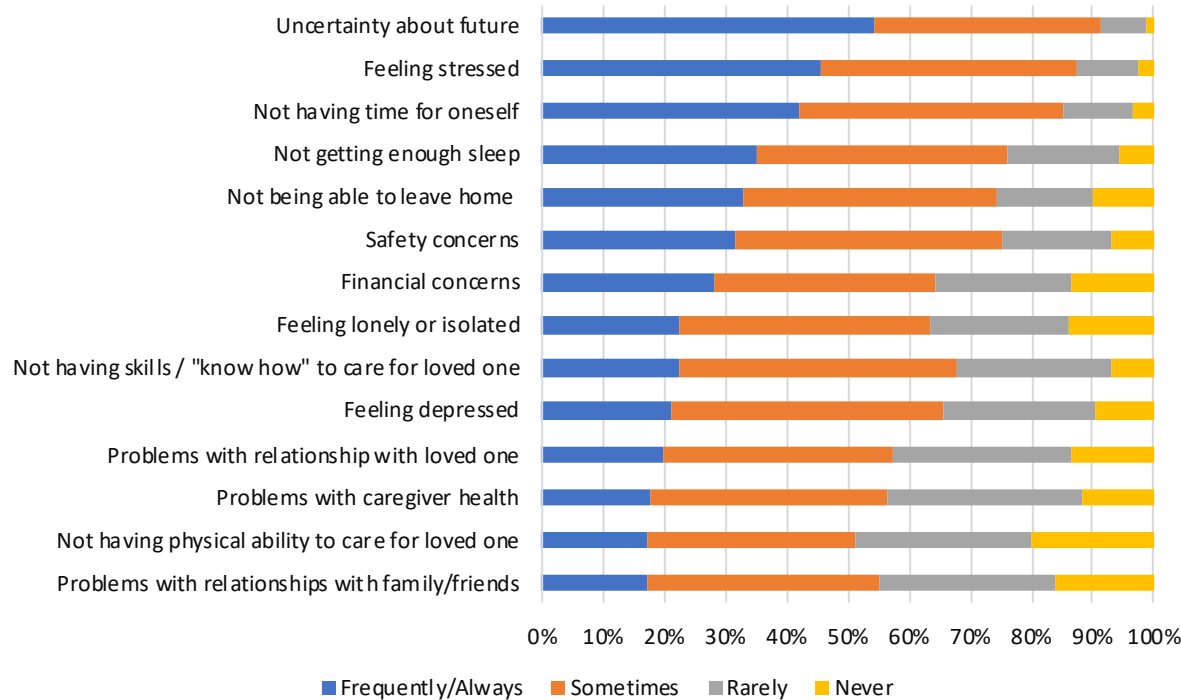
## Methods:

- Two surveys were developed to explore caregiver burdens and interactions with HCPs.
- The surveys were sent to members of two virtual research communities, ACP's iConquerMS network and UsAgainstAlzheimer's A-LIST<sup>®</sup> registry.

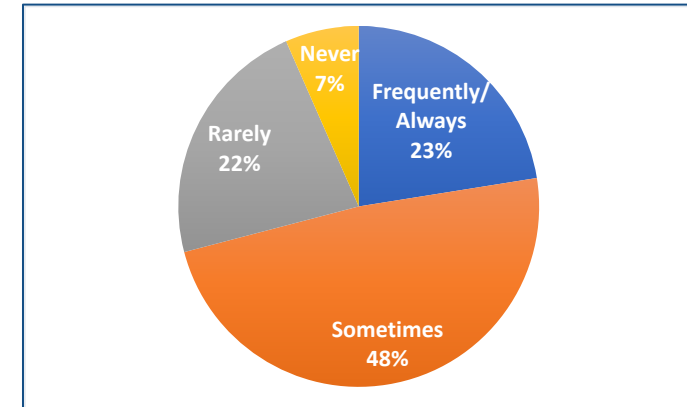
# Results – Caregiver Burdens Survey

- 568 current/former caregivers participated in the caregiver burdens survey (413 AD, 117 MS, 38 other)
- 129 non-caregivers also participated
- 69% female, 30% male; 89% age 51 or older
- 83% Caucasian, 8% African-American, 6% Latino, 1% Asian

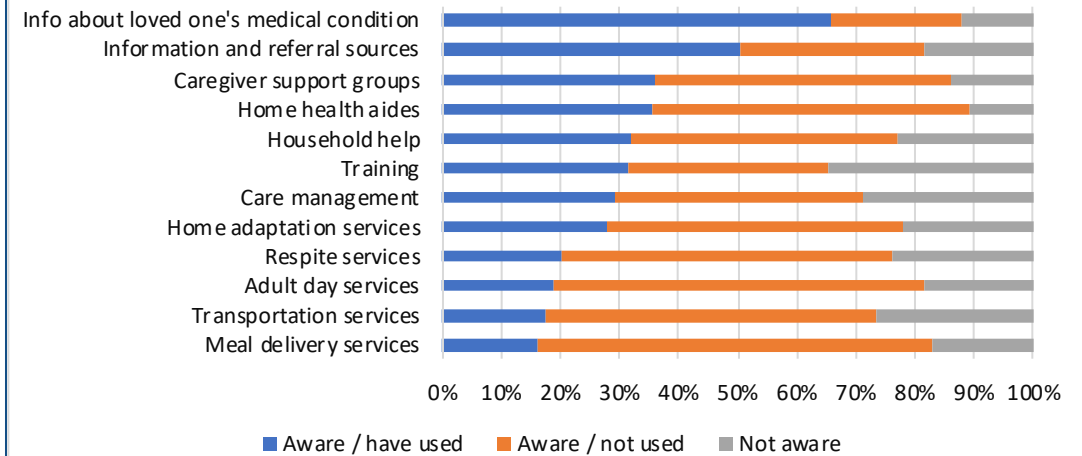
Types of Burdens Experienced by MS/AD Caregivers



Frequency of Access to Sources of Help or Support with Caregiving Burdens



Caregiver Services - Awareness and Usage



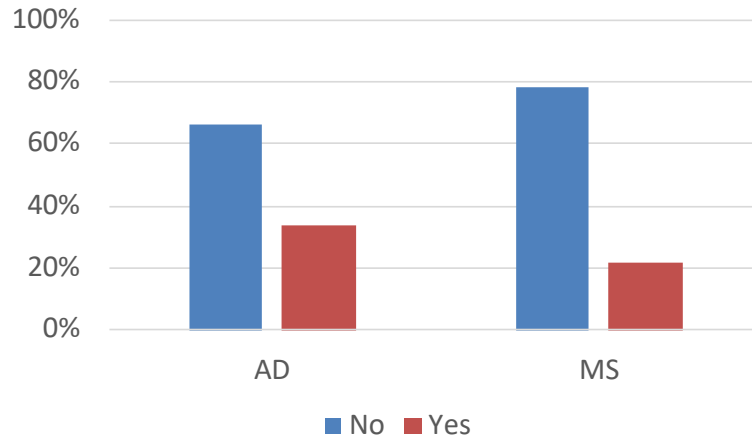
# Results – Caregiver / HCP Interactions Survey

- 683 current/former caregivers participated in the caregiver / HCP interactions survey (473 AD, 158 MS, 52 other)
- 213 non-caregivers also participated
- 71% female, 29% male; 90% age 51 or older
- 85% Caucasian, 10% African-American, 5% other/multiple race; 7% Latino

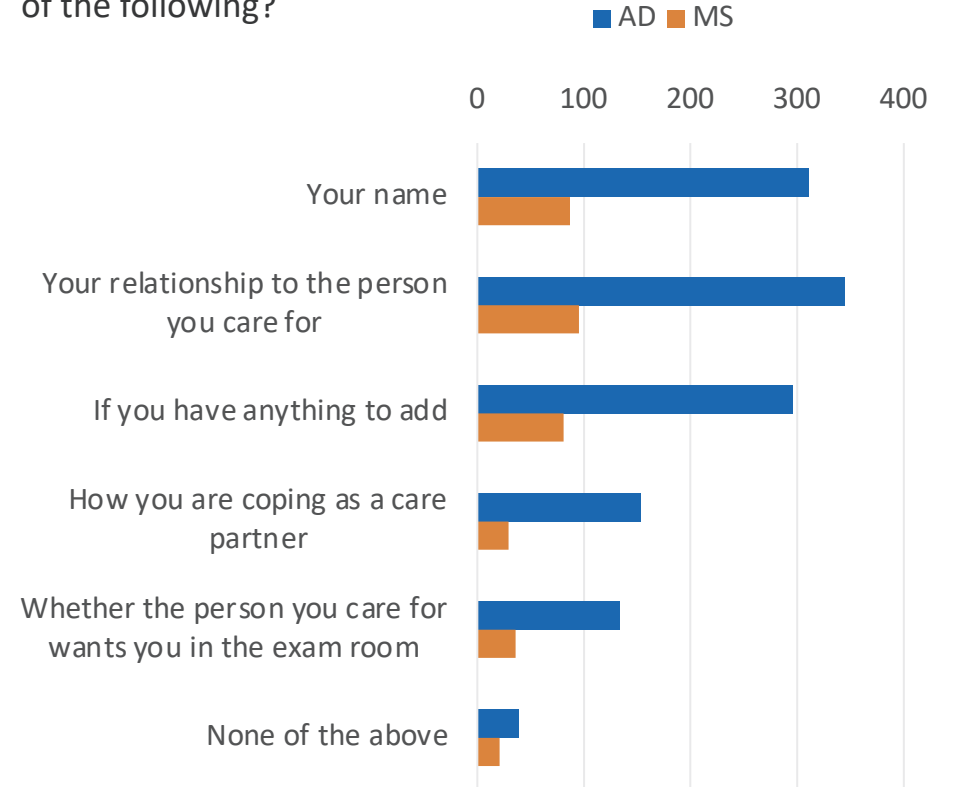
Have you received any training, or information about receiving training, to better prepare you as a care partner?

Caregiver info/training received	MS	AD
No information or training	83.1%	68.6%
Information	9.1%	12.0%
Training	3.9%	6.6%
Information & training	3.9%	12.8%

Has YOUR OWN healthcare provider ever given you help or advice about being a care partner, or suggested where you might get help?



Has the main HCP (of the MS or AD patient) ever asked any of the following?



Did the HCP make accommodations in order to overcome a language barrier?

Yes	5%
No	6%
No need	88%

# Conclusions

- › MS and AD caregivers face a common set of burdens, and often must face these challenges without the benefit of formal training or reliable support.
- › Common sources of stress for MS and AD caregivers include uncertainty about the future, feeling stressed, and not having time for oneself.
- › Most caregivers have not received any training to prepare them for being a caregiver, including from their own healthcare provider.
- › Healthcare providers for the person with MS or AD rarely ask caregivers how they are coping and whether the patient wants them in the examination room, and don't always ask the caregiver's name or relationship to the patient. Language barriers are often not offered when needed.
- › Healthcare providers can help by inquiring about challenges faced by their patients' caregivers and providing information and referrals to available resources.

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