
The Alzheimer's Caregiver Perspective

Report of Survey Findings

Prepared for:

Novartis Pharmaceuticals Corporation &
The Alzheimer's Foundation of America

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Research Method

The findings reported here are based on online interviews with 339 adult family caregivers of Alzheimer's disease patients. Participants are members of the Harris Interactive online panel. Caregivers qualifying for participation in the study had to be at least somewhat involved in the care or day-to-day activities of the AD patient, and had to accompany the patient on visits to the doctor. Harris Interactive conducted the online survey between January 6 and 12, 2004, using a self-administered online questionnaire averaging 10 minutes in length.

In theory, with probability samples of this size, one can say with 95% certainty that the results have a sampling error of plus or minus 5 percentage points of what they would be if the entire U.S. population of adult AD caregivers had been polled with complete accuracy. This online sample was not a probability sample.

¹ 75% of respondents indicated that they are involved in the patient's care "a great deal."



Summary of Conclusions

Overall, the AD caregivers participating in this study feel that they and the patient's doctor are a team. Most respondents believe the physician has explained disease progression and what to expect in terms of how symptoms manifest. However, the findings suggest there is room for even more doctor-caregiver communication, especially when it comes to treatment options. Only half of respondents feel the doctor explained treatment options "very well" and fewer than half are sure that the doctor told them about all available treatments. Satisfaction with doctor-caregiver communication is directly related to caregiver involvement: Caregivers who are highly involved in treatment decisions are much more likely than others to be satisfied with their overall communication with the doctor.

A majority of caregivers surveyed said that the patient for whom they provide care has taken prescription medication for his or her Alzheimer's at some point in time. Most of these respondents said that the patient is still on treatment. Efficacy far outweighs other concerns as the most important component of AD medication, and efficacy regarding behavioral symptoms and ability to carry out daily activities is markedly more important to caregivers than efficacy regarding cognitive symptoms.

Alzheimer's disease significantly impacts the life of the active caregiver, and relatively few have sufficient support. While most caregivers are interested in more community services to support them, few have actually reached out to support organizations for help.



Key Findings

Physician-Caregiver Interaction

Overall, the AD family caregivers participating in this study feel that they and the patient's doctor are a team. Most respondents believe the physician has explained disease progression and what to expect in terms of how symptoms manifest. However, the findings suggest there is room for even more doctor-caregiver communication.

Physician-Caregiver Interaction/AD and AD Resources:

- Most (70%) of the respondents say the doctor has explained disease progression and how symptoms will manifest.
 - However, as many as 30% have not received this information from the treating physician.
 - And, caregivers would have appreciated *more* information of this kind at the time of diagnosis. Of nine types of information they would have wanted more of at the time of diagnosis, information on disease progression is most often ranked #1 by respondents.
- Approximately half (55%) of respondents say the doctor has provided non-treatment-related information (e.g., advice on how to provide care), but as many as 45% do not recall receiving such information.



Key Findings

Physician-Caregiver Interaction (cont'd)

Physician-Caregiver Interaction/AD Treatment:

- Only half of respondents say the doctor has explained AD treatment options to them “very well.”
 - Most say the doctor explained treatment options at least “somewhat well.”
- Fewer than half (48%) of the caregivers surveyed say the physician provided them with information about *all available* AD medications.
- Among respondents who said that the patient for whom they provide care has taken an AD medication:
 - Fewer than half (44%) report that the doctor asks for their input on how well the medication is working; but, a higher percentage (57%) say they proactively offer the doctor feedback on this without being asked.
 - The majority (77%) say the physician has given them realistic expectations about what to expect from the treatment.
- Overall, most (73%) respondents describe a high level of cooperation with the patient’s doctor when it comes to making decisions about treatment:
 - Either the doctor tells them about different treatment options and the physician and caregiver make decisions together (47%) or the doctor at least gives them a say in the treatment decision (26%).
 - Of the 39% of caregivers who have proactively requested a specific medication, most (85%) report the physician complied with this request.
- Caregivers who are highly involved in treatment decisions are much more likely than others to be satisfied with their overall communication with the doctor.





Key Findings

Treatment Priorities

A majority of caregivers surveyed said that the patient for whom they provide care has taken prescription medication for his or her Alzheimer's. Most of these respondents said that the patient is still on treatment. Efficacy far outweighs other concerns as the most important component of Alzheimer's medication, and efficacy regarding behavioral symptoms and ability to carry out daily activities is markedly more important to caregivers than efficacy regarding cognitive symptoms.

- Approximately three-quarters of caregivers surveyed (77%) say the patient for whom they provide care has taken a prescription medication to treat the symptoms of the disease; among these caregivers, most (68%) say the patient is still taking medication.
- According to caregivers, nearly half of patients who have taken medication (47%) have switched drugs at some point. The primary reason for switching is efficacy.
- Among caregivers who say the patient has taken medication, the vast majority (77%) rank efficacy as the most important aspect of treatment. Freedom from side-effects (ranked #1 by only 14%), affordability (7%), and convenience (3%) are comparatively much less important.
 - These caregivers underscored the importance of efficacy, explaining that if they had to choose a trade off, they would choose better efficacy over other factors.
 - An overwhelming 94% to 6% majority would choose a medication with better efficacy that has to be taken more than once-a-day over less efficacy in a medication that is taken only once-a-day.





Key Findings

Treatment Priorities (cont'd)

- A solid 61% to 39% majority said they would choose a medication with better efficacy and a higher side-effect potential over lower efficacy with a lower side-effect potential.
- Efficacy specific to behavioral symptoms and activities of daily living are viewed as more important than efficacy relative to cognitive symptoms: about one-third of these caregivers, respectively, rank “unpredictable behavior” (35%) and problems with activities of daily living (34%) first on the list of desired improvements brought about by medication, compared with only about half that percentage, respectively, who rank “impaired ability to think or reason” (16%) or memory loss (16%) in first place.
- Overall, a third of caregivers agree that medical treatment for their AD patient has improved their own daily lives; those caring for a patient that currently takes Rx medication are significantly more likely to feel this way.



Key Findings

The Caregiver's Burden / Need for Information and Support

Alzheimer's disease significantly impacts the life of the active caregiver, and relatively few have sufficient support.

While most caregivers are interested in more community services to support them, few have actually reached out to support organizations for help.

Impact on the Caregiver:

- Nearly all respondents (94%) say that caring for someone with Alzheimer's disease has changed their lifestyle at least somewhat; 70% say that it has changed their life "a great deal."
- Most (85%) also say that caring for a relative with AD has somewhat changed the way they experience specific events at least somewhat; 54% say it has changed the way they experience specific events "a great deal."
- Almost all caregivers say they feel overwhelmed by the patient's condition (81%) and most worry that they are the patient's only source of care (68%).
- Indeed, many caregivers seem to be "going it alone": Only one half or fewer rely even somewhat on an outside source such as a home health aid (50%) or family and friends (45%) for help in providing care to the patient.

Caregiver Support Services:

- A majority of caregivers in the study (62%) say they are interested in more community support services, yet only one in four (25%) has joined an Alzheimer's disease caregivers support group.
- Approximately half (53%) of the caregivers who belong to a support group say that it has improved their daily life at least "somewhat"; approximately half (47%) of these caregivers say that support services have improved daily life for the person with Alzheimer's disease.
- Most caregivers appear to have learned about their support group through AD organizations (51% of those who have joined a support group); few say they heard about their support organization through the doctor's office or other sources (no more than one in five).