Assessing Self-Reported Health and Quality of Life in Ethnically Diverse Caregivers for People with Agitation in Alzheimer's Dementia

Reese, Emily S[1]; Eisenberg, Debra F[2], Wang, Jinyi[3]; Waters, Heidi C[1]; Chumki, Sanjeda R.[1]; Wang, David[2]; Richardson, David[3]

[1]Otsuka Pharmaceutical Development & Commercialization, Inc., Princeton, NJ, USA; [2]Lundbeck, LLC., Deerfield, IL, USA; [3]RTI Health Solutions, Research Triangle Park, NC, USA

Poster presented at the ISPOR Annual Meeting
May 17 – 20, 2026
Philadelphia, PA

Introduction

- Alzheimer's disease is a progressive neurodegenerative disorder that is the most common cause of dementia in older adults.[1]
- Neuropsychiatric symptoms are common in Alzheimer's dementia. Symptoms include apathy, agitation, and irritability.[2]
- The International Psychogeriatric Association defines agitation associated with dementia due to Alzheimer's disease as manifestations of excessive motor activity, verbal aggression, or physical aggression that are consistent with emotional distress for the person concerned, cause excess disability, and are not totally attributable to another disorder.[3]
- Informal caregivers (e.g., family members, friends) play an important role in the care of individuals with agitation in Alzheimer's dementia.[4]
- Agitation-related symptoms are related to caregiver burden, and associated with negative outcomes among caregivers, such as decline in their general health, quality of life, and social isolation.[5-7]

Study Objective

- To understand self-reported quality of life, including physical, mental, and social health among informal caregivers of people with agitation in Alzheimer's dementia across diverse racial/ethnic groups.

Methods

This was a non-interventional observational study, which included a cross-sectional web-based survey of culturally diverse adult caregivers of an individual with agitation in Alzheimer's dementia who reside in the United States (US).

Participants

- Participants were recruited through a panel vendor with experience recruiting diverse participants across multiple disease areas; patient advocacy groups, social media, online advertising, social media influencers, referral programs, consumer panels, databases of previous respondents, and patient ambassadors.
- Potentially eligible participants received a study invitation via email from the panel vendor and were directed to a web-based screening questionnaire using a unique link. If eligible, participants provided informed consent to continue with the survey.
- Participants were required to be 18 years old or older, provide at least 5 hours per week of unpaid care for a person with agitation in Alzheimer's dementia, provide informed consent, and able to read/respond to the survey questionnaire in English, Spanish, or Mandarin Chinese.
- To ensure a diverse sample of caregivers, quotas were set for different racial/ethnic groups to approximate the overall percentages in the US population, with oversampling for African American/Black, Latino, and Asian/Asian American groups.

Survey Methods

- The web-based questionnaire was self-administered and could be completed over multiple sessions. Participants were compensated $63 for their time spent completing the survey.

Statistical Analysis

- Descriptive analyses were used to summarize questionnaire responses from the entire sample of caregivers and from racial/ethnic groups. Numbers and percentages were reported for categorical data, while the number responding (N), mean, standard deviation, median, quartiles (first and third), and range were reported for continuous data.
- All data analyses were performed using SAS 9.4 or higher statistical software (SAS Institute, Cary, NC; 2010).

Results

Demographics

- A total of 200 people completed the survey. Of the 200 overall respondents, 28% were White, 20% Latino, 17.5% African American/Black, 15.5% Asian/Asian American, 9.5% Alaska Native/American Indian/Native American, 2.5% Middle Eastern/North African, 2.5% Native Hawaiian/Pacific Islander, and 4.5% endorsed 2 or more races.
- The majority (67.0%) were female, and mean age was 46 years, with age and gender varying by subgroup.
- Most caregivers (60%) were in parent/child relationships, while 9.0% reported caring for a spouse, 2% for a sibling, 17% for another relative, 4.5% for a friend, and 4% for another non-relative.
- Three-quarters (75.5%) of respondents lived in the same household as the person they were caring for, and 30% had been providing care for longer than 5 years.
- Demographics captured from the screening population are presented in Table 1. Results from the targeted populations are presented throughout.

Quality of Life

- Of the overall sample, 74% rated their quality of life as good, very good, or excellent. While 84.5% rated their physical health positively, and 75.5% rated their mental health positively, only 52% of respondents rated their social health as good, very good, or excellent. There were differences among the various racial/ethnic groups.
- Approximately 30% of White respondents also ranked their social health as "fair" or "poor", compared to those from African American/Black and Asian/Asian American respondents, who generally rated their quality of life higher, with around 20% endorsing "fair" or "poor". (Figure 1a)
- A higher percentage of Asian/Asian American (22.6%) and African American/Black (20.0%) respondents rated their physical health as "fair" or "poor" than the other subgroups. (Figure 1b)
- A higher percentage of White (26.8%) and Asian/Asian American (25.8%) respondents rated their overall mental health as "fair" or "poor", while Latino, African American/Black respondents rated their mental health higher (~20% endorsing "fair" or "poor"). (Figure 1c)
- Ratings of social health were lower across all racial/ethnic groups, with lowest ratings among White (34.3%), African American/Black (37.2%), and Latino (33.0%) respondents ranking their social health as "fair" or "poor". (Figure 1d)
- Across all domains, Middle Eastern/North African and Native Hawaiian/Pacific Islander respondents had the lowest percentages of "fair" or "poor" responses, indicating generally positive self-assessment. However, sample sizes in these populations were low (n=5), so results should be viewed with caution. None in either subgroup rated their physical or mental health as fair or poor.

Self-Care & Support

- When asked how often caregivers did things for themselves during the past month, 67% (95% CI 60.2%, 73.3%) reported sometimes, often or always, with the highest percentage among Middle Eastern/North African caregivers (100% [95% CI, 47.8%, 100%]), and the lowest among White caregivers (53.6 % [95% CI: 36.7%, 67.2%).
  - The vast majority (71.5% [90% CI 64.7%, 77.6%]) of caregivers reported they do not have enough time for social activities
- When asked to choose from a list of 8 support types that would help with caregiving responsibilities, caregiver emotional support (66.2% overall; White=72.3%; African American/Black=71.4%) and patient emotional support (60.2% overall; Asian/Asian American=71.0%; Alaska Native/American Indian/Native American=63.2%) were endorsed the most. (Figure 2)

Caregiving Duties

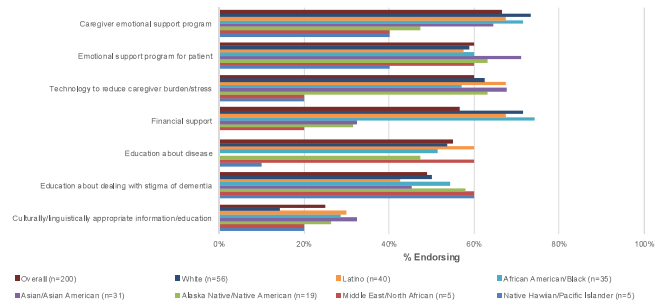
- Approximately 60.5% of respondents reported spending over 40 hours per week on caregiving responsibilities.
- Respondents spent a mean (SD) of 19.5 (24.1) hours per week helping with household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances and legal affairs, and answering the telephone.
  - White respondents reported the highest number of mean hours (32.3 [34.3]) on these chores, and the Middle Eastern/North African cohort the least (4.4 [3.2]).
- An additional 14.4 (12.3) hours were spent managing behaviors (e.g., aggressive behaviors, wandering, depressive mood, agitation, anxiety, repetitive behavior, nighttime disturbances, etc.), with 41.3% of respondents indicating that they thought they should spend more time helping with these.
  - While (20.9 [24.8]) and African American/Black (17.0 [24.3]) caregivers reported spending the most time managing agitation-related symptoms, while Middle Eastern/North African (3.0 [1.4]) and Asian/Asian American (5.1 [4.8]) caregivers reported the least time.
- They used non-overspent hiring and supervising others to provide care (152.5 [1hours per week]) and finding and using supportive care such as support groups or adult day centers (53.0 [50.5]) hours per week). However, about 40% of respondents felt they should spend more time) asking this such services.

Table 1: Demographics - Screened Population

	Overall N=200		White N=56		Latino N=40		AA/B N = 35		A/AA N=31		NA/AI N=19		MENA N=5		NHPI N=5		2 or More Races* N=9	
	N	%/SD	N	%/SD	N	%/SD	N	%/SD	N	%/SD	N	%/SD	N	%/SD	N	%/SD	N	%/SD
Gender (Female)	135	67.5	50	89.3	29	72.5	31	88.6	10	32.3	8	42.1	2	40.0	0	0	5	55.6
Age, Mean (SD)	45.6	13.2	48.8	12.8	42	11.3	48.4	13.1	39.6	8.5	49.4	16.1	59.2	19.7	44.4	7.9	4	44.4
Employed																		
Yes	136	68	29	51.8	29	72.5	22	62.9	27	87.1	14	73.7	5	100.0	5	100.0	5	55.6
No	64	32.0	27	48.2	11	27.5	13	37.1	4	12.9	5	26.3	0	0	0	4.0	4	44.4
Relationship to person with agitation in Alzheimer's disease?																		
Spouse/partner/significant other	19	9.5	7	12.5	0	0	2	5.7	4	12.9	3	15.8	1	20	1	20	1	11.1
Parent	78	39	22	39.3	18	40	15	42.9	11	35.5	5	26.3	2	40	3	60	4	44.4
Sibling	4	2	0	0	1	2.5	1	2.9	1	3.2	1	5.3	0	0	0	0	0	0
Child	48	24	16	28.6	12	30	11	31.4	4	12.9	3	15.8	0	0	0	0	2	22.2
Friend	9	4.5	1	1.8	1	2.5	2	5.7	2	6.5	2	10.5	1	20	0	0	0	0
Other relative	34	17	8	14.3	7	17.5	3	8.6	8	25.8	5	26.3	1	20	0	0	2	22.2
Other non-relative	8	4	2	3.6	3	7.5	1	2.9	1	3.2	0	0	0	0	1	20	0	0
How long caring for person with agitation in Alzheimer's disease																		
Less than 6 months	2	1	0	0	0	0	35	0	1	3.2	0	0	0	0	0	0	0	0
6 months to 1 year	32	16	3	5.4	8	20	1	2.9	7	22.6	4	21.1	1	20	3	60	3	33.3
1 to 3 years	68	34	16	28.6	17	42.5	3	8.6	15	48.4	9	47.4	2	40	0	0	2	22.2
3 to 5 years	46	23	14	25	7	17.5	7	20	3	9.7	3	15.8	2	40	2	40	3	33.3
More than 5 years	52	26	23	41.1	8	20	12	34.3	5	16.1	3	15.8	0	0	0	0	1	11.1
Live in the same household?																		
Yes	151	75.5	41	73.2	27	67.5	26	74.3	25	80.6	17	89.5	4	80	4	80	7	77.8
No	49	24.5	15	26.8	13	32.5	9	25.7	6	19.4	2	10.5	1	20	1	20	2	22.2

*Added for comparison
SD= Standard deviation; AA/B = African American/Black; A/AA = Asian/Asian American; NA/AI = Native American/American Indian; MENA = Middle Eastern/North African; NHPI = Native Hawaiian/Pacific Islander

Figure 2. Caregiving Support Needed



NOTE: Data for respondents identifying as "2 or More Races" were not included as a separate category in graphs; however, their data are represented in the "Overall" category.

Figure 1a. Self-report Rankings of Quality of Life

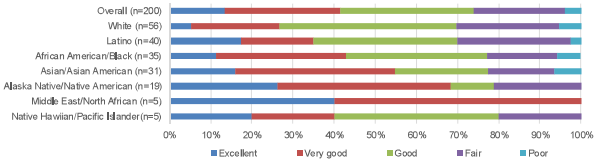


Figure 1b. Self-report Rankings of Physical Health

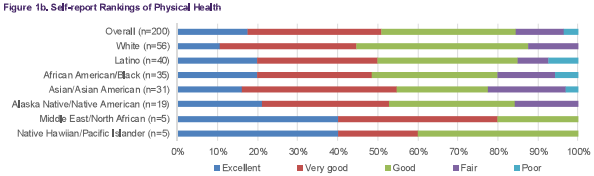


Figure 1c. Self-report Rankings of Mental Health

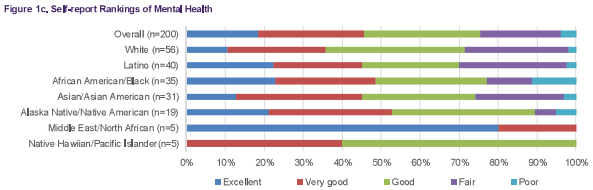
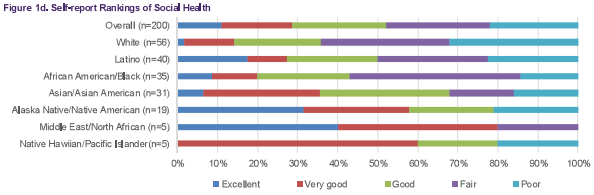


Figure 1d. Self-report Rankings of Social Health



Limitations

- Because the sample of 200 participants was divided across several racial/ethnic subgroups, it was not possible to make statistical inferences between subgroups, as the number of participants in specific subgroups was too small.
- A limitation of this study and all voluntary surveys is potential responder bias. The study sample reflects a convenience sample, which could lead to skewed results.
- Study results were based on caregiver self-report and, therefore, recall bias may have led to inaccuracies in the data.
- Stage and severity of Alzheimer's disease and its symptoms, as well as concurrent medical conditions in the caregiver and patient, may have influenced self-report ratings of health and quality of life. Therefore, results should be interpreted with caution.
- The study results may not be generalizable to the agitation in Alzheimer's dementia caregiver population outside of the US.

CONCLUSIONS

Most respondents rated their overall physical health, mental health, and quality of life as good/ very good/ excellent; however, only about half rated their social health as good, very good, or excellent.

- This was congruent with other literature showing that symptoms of Alzheimer's dementia, including agitation-related symptoms, are associated with negative quality of life and social isolation for the caregiver.[4-6]
- That study also found that many caregivers of people with Alzheimer's dementia become isolated from family members and friends because they do not leave their family members at home alone, nor do they go out with them.[6]

White and African American/Black participants rated their quality of life and social health lower than other ethnic subgroups, while White and Asian American respondents rated mental health lower.

Caregivers also reported that they wished they had more emotional support for themselves and the person they were caring for.

- These findings are supportive of earlier research which found that White, African American/Black, and Latino caregivers expressed a need for non-medical-related resources, including assistance with basic needs, caregiving support, caregiving time off to rest, and additional social activities and companionship for the person being cared for.[6]
- Similarly, another survey showed that almost half of the respondents wanted additional caregiving support and time off to rest or go on a vacation.[7]

Culturally/ linguistically appropriate information or education was not endorsed highly by participants.

Support that allows caregivers to reduce their levels of social isolation, whether it be additional caregivers, social programs, or respite care, may help improve the quality of life and reduce burden among caregivers.

References

1. National Institute of Health Alzheimer's Disease Fact Sheet. 2023. Available at https://www.nih.gov/health-information/nih-staff-health-topics/alzheimers-disease-fact-sheet. Accessed November 9, 2025.
2. Zhao QF, Tan L, Wang HF, Jiang T, Tan MS, Tan L, Xu W, Li JQ, Wang J, Lai TJ, Yu JT. The prevalence of neuropsychiatric symptoms in Alzheimer's disease: Systematic review and meta-analysis. J Affect Disord. 2016 Jan 15;190:264-271. doi: 10.1016/j.jad.2015.09.069.
3. International Psychogeriatric Association, Neve and Brue Defining Agitation. Available at https://www.ipa-psychi.org/ipa-psychi-in-action/agitation. Accessed April 14, 2026.
4. Itoh A, et al. Bidirectional relationship between caregiver burden and neuropsychiatric symptom in patients with Alzheimer's disease: a narrative review. International Journal of Geriatric Psychiatry 2018;34(9):1329-1334.
5. Tran, J.Y., Theng, B., Tseng, H.M., Raj, M., Seng, H., Shih, M., Kane, W.M. (2022). Cultural diversity impact caregiving experiences: A comprehensive exploration of differences in caregiver burdens, needs, and outcomes. Clinical, 10, 10, 4653-7. https://doi.org/10.21037/tcr-22-1657
6. Chester, M., Gaudreau, Leblanc, M., Gagnon-Sanschagrin, P., Guerin, A., Harty, K., Bolton, R.A., Duffy, R., Gwin, K., Aigbogun, M.S., and Alzheimer's Disease Neuroimaging Initiative. 2019. Institutionalization and caregiver stress associated with agitation in Alzheimer's disease. Alzheimer's & Dementia Translational Research & Clinical Interventions. 5, pp. 88-98.

Disclaimer

This study was funded by Otsuka Pharmaceutical Development & Commercialization, Inc. and Lundbeck, LLC. Emily S. Reese, Heidi C. Waters, and Sanjeda Chumki are employees of Otsuka Pharmaceutical Development & Commercialization, Inc. and Debra F. Eisenberg and David Wang are employees of Lundbeck, LLC. Jinyi Wang and David Richardson are employees of RTI International, which was paid by Otsuka and Lundbeck to conduct the study.