Assessing Priorities in Ethnically Diverse Caregivers of People with Agitation Associated with Alzheimer's Dementia

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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.
- The International Psychogeriatric Association defines agitation 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 solely attributable to another disorder.[2]
- Informal caregivers (e.g. family/friends) play an important role in the care of individuals with agitation in Alzheimer's dementia. They face many challenges in managing the health of the one they care for as well as their own health and other stressors (e.g., physical, emotional, and financial burdens).[3]
- Agitation is a leading cause of institutionalization into higher-level residential care facilities for patients with Alzheimer's dementia.[4,5]

Study Objectives

Primary Objective

- To describe the priorities, needs, burdens, and stressors associated with caregiving for individuals with agitation in Alzheimer's dementia across racial/ethnically diverse caregiver groups with a specific focus on caregiver desire to keep the person with agitation living at home.

Secondary Objective

- To describe caregiver demographic & sociodemographic characteristics, current caregiving duties/feelings, behaviors that accompany caregiving, and amount of caregiving help provided by friends and family.

Methods

This was a non-interventional observational study, which included a cross-sectional web-based survey of culturally diverse adult caregivers of individuals 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, 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 10 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 ethnic/racial 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 $50 for their time spent completing the survey.

Statistical Analysis

- Descriptive analyses summarized questionnaire responses from the entire sample of caregivers & from racial/ethnic subgroups. Numbers/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 analyses were performed using SAS 9.4 (or higher) statistical software (SAS Institute, Cary, NC 2013).

Results

Demographics

- A total of 200 people completed the survey. Of those, 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% reported more than 2 races. Demographics captured from the screening population are presented in Table 1. Results from the targeted populations are presented throughout.
  - The majority (67.2%) were female, and mean age was 45.6 years, with age and gender varying by subgroup.
  - Most caregivers (82%) were in parent/child relationships, while 9.5% reported caring for a spouse, 2% for a sibling, 17% for another relative, 4.2% 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.

Primary Objective: Keeping loved ones at home

- Overall, 92.5% (95% CI: 87.8%, 95.7%) of caregivers felt it was important or very important to keep the one they cared for at home rather than in a long-term care facility (LTC), which was consistent across all subgroups.
- However, 28% (95% CI: 22.8%, 35.8%) of caregivers reported that family and/or friends did not want the person at home.
- Differing opinions in the desire to keep the person with agitation at home to 81.2% (95% CI: 67.4%, 91.1%) of caregivers feeling additional burden and stress.
- Respondents were asked how strongly they identified with different pressures to keep the person they were caring for at home. Self-pressure was endorsed the highest among all subgroups (71.5%; 95% CI: 65.1%, 76.0%), especially Native Hawaiian/Pacific Islander (80%; 95% CI: 28.4%, 99.5%), Latino (77.5%; 95% CI: 61.5%, 89.2%), and White (78.4%; 95% CI: 63.0%, 88.8%) cohorts. (Figure 1)
  - Cultural pressure (CP) and family pressure (FP) were also highly endorsed across subgroups, with higher endorsement among Native Hawaiian/Pacific Islanders (80.0% CP, 80.0% FP), Asian/Asian American (68.9% CP, 67.7% FP), and American Indian/Native American (47.4% CP, 52.6% FP) subgroups. (Figure 1)

Caregiving Assistance

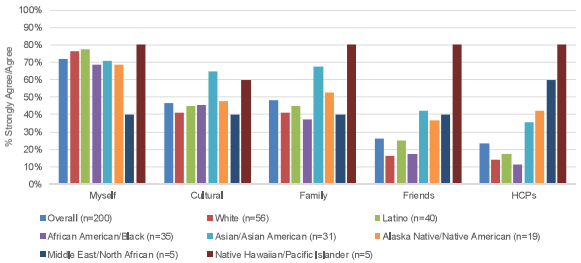
- Overall, 44.5% of respondents received assistance from other unpaid caregivers, with African American/Black (37.1%), White (37.0%), and Latino (40%) caregivers being the least likely to have unpaid assistance with caregiving. A mean (SD) of 1.8 (1.16) other unpaid people supported the respondents, with spouses (23.5%) or siblings (22.5%) most often cited as the source of that help.
- Of those who sought unpaid help, feeling overwhelmed was the most common reason among the overall sample (60.4%). The person with agitation’s memory decline, agitation symptoms, and impaired understanding of disease were also common reasons for seeking help from others. (Figure 2)
- Overall, 46.5% caregivers sought support from a paid caregiver, with more than half of caregivers in all subgroups except for White caregivers (41.1%) reporting that they paid for additional support.
- Feeling overwhelmed (49.5%) was the most common reason for asking for paid assistance, but 52.5% of caregivers reported it was either “Difficult” or “Very difficult” to seek paid care.
- Caregivers face many barriers to seeking paid help. Finances (64%) was the main barrier, especially among White (76.8%) and African American/Black caregivers (74.2%). (Figure 3)
  - Other top barriers to seeking help included fear about what others (including the loved one with agitation in Alzheimer’s dementia) would think (30.0%), and having difficulty not knowing where to find paid assistance (29%). (Figure 3)
- Primary caregivers did not get much relief from caregiving. Even with assistance, the primary caregiver was present 32.3% of the time when other unpaid caregivers were helping and 48.5% of the time when paid assistance was being provided.
- Only 25% of caregivers reported that the person they care for attends a senior center, but that percentage was less for White (8.9%), African American/Black (17.1%), and Latino (22.5%) subgroups.
  - The number of hours per week spent in senior centers varied widely (44.2 hours for the African American/Black subgroup to 4 hours for the Middle Eastern/North African subgroup), with an overall average of 14.3 hours per week.

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 dementia?																		
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 dementia																		
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 1: Sources of Pressure to Keep Individuals Cared for at Home



HCP = Healthcare Provider.

Figure 2: Reasons For Seeking Unpaid Assistance

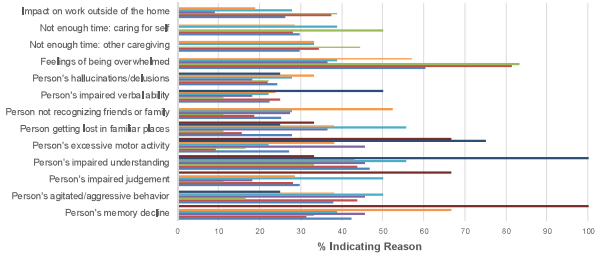
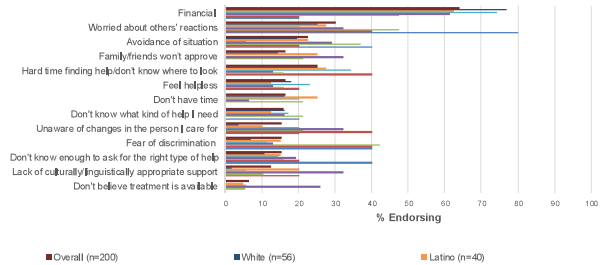


Figure 3: Barriers to Seeking Paid Assistance



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.

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 were too small.
- A limitation of this study and all inflammatory surveys is potential respondent 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 different 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

Informal caregivers play an important role in the care of individuals with agitation in Alzheimer’s dementia, and over 90% of caregivers across racial/ethnic groups in our survey felt it was important to keep the person they were caring for at home vs. placing them in an LTC setting.

- Pressure to keep loved ones at home came from many different sources and varied among subgroups.

Less than half of caregivers had assistance with caregiving duties, and asking for help was difficult.

- Barriers to seeking help included finances, fear of what others would think, and not knowing where to find assistance; barriers differed among subgroups.

Feeling overwhelmed was the main reason for seeking help. Symptoms of memory decline and agitation were also common reasons for seeking help from others.

There were differences among racial and ethnic groups in terms of caregiving experiences. A greater understanding of these differences will help in the development of programs to support caregivers of people with agitation in Alzheimer’s dementia.

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Disclaimer

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