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Caring for the Caregivers: An Alzheimer’s Disease Research Center Call to Action

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Abstract

Currently, over 16 million dementia caregivers in the US provide over 18 billion hours of care. As the number of persons living with dementia increases, so too will the number of family caregivers. Given the projected steady growth in caregivers and their health-related needs in caring for persons living with Alzheimer’s disease and related dementias, several initiatives are underway that focus on caregivers. One overlooked mechanism to meet caregiver needs is the National Institute on Aging’s Alzheimer’s Disease Research Centers (ADRCs). Through secondary analysis, we present a picture of dementia caregiving from the National Alzheimer’s Coordinating Center’s database and discuss a call to action for ADRCs to engage caregivers and further support the mission of the ADRC to advance the field of dementia research.

Keywords

Caregivers; ethnic/racial; Alzheimer's Disease; ADRC; NACC

Introduction

In the United States over 6 million persons are living with Alzheimer's Disease and Related Dementia (ADRD), with projections to rise exponentially within 20 years.¹ As the number of persons living with dementia increases, so too will family caregivers. Currently, over 11 million dementia caregivers in the United States provide over 15 billion hours of care, often at the expense of their mental and physical health.¹ The stressful impact of caregiving is attributed to long-term caregiving and variability in the disease trajectory and care recipient needs.² In communities of color, the impact of caregiving may be exacerbated due to cultural values and environmental contexts, including social determinants of health.³ In addition to care provision, increased demands of medical/nursing care tasks further the caregiving impact; although our understanding remains limited.^{4, 5}

Given the rise in caregivers and their health-related needs, the National Institute on Aging's (NIA) 2020 Research Summit on Dementia Care highlighted potential areas in future research, including engaging person's living with dementia and their family caregivers in research.⁶ One underused mechanism to address this recommendation includes Alzheimer's Disease Research Centers (ADRCs). For over 30 years, NIA funded ADRCs were established to focus on dementia research and treatment.⁷ Specifically, ADRCs foster environments of opportunity and innovation in research, education, and training for all involved in the dementia field, including caregivers.⁷ Each ADRC includes an Outreach Recruitment and Engagement (ORE) core with a focus on bi-directional engagement between participants, caregivers, and the community, emphasizing diverse populations.⁷ In addition to the innovative work currently being done, inclusive research of diverse populations of caregivers would advance the ADRD field, elucidate challenges, and inform interventional studies to better support caregiver needs. We describe dementia caregiving in diverse populations and discuss an opportunity for ADRCs to engage caregivers, further supporting the mission of ADRCs advancing the field of dementia research.

Methods

This secondary data analysis examined the National Alzheimer's Coordinating Center's (NACC) database of NIA supported ADRCs to describe dementia caregiving in diverse caregivers. The NACC database approximately annually collects standard clinical data from participants at all existing ADRCs, plus information through co-participants. A comprehensive description of the NACC database can be found elsewhere.⁸ NACC data for visits conducted between September 2005 and August 2018 were analyzed in August 2019. Descriptive statistics were used to examine demographic and caregiving data variables and were included only for individuals with a confirmed diagnosis of dementia at baseline. In the absence of a caregiver burden measure, the following questions were used as a proxy: "Does

the co-participant live with the participant?" If the answer was no, frequency of in-person visits and telephone contact were also assessed.

Independent from NACC data, to explore caregiver engagement within the ADRCs, a one-time 10-item questionnaire including open-and-closed-ended questions was distributed to ORE Core leaders in September 2019 in advance of the Fall ORE meeting using the ORE listserv. Questions in this analysis included: (1) ORE Core frequency of, and opportunities for, caregiver outreach and engagement in research, education, and workshops/support groups; (2) what type of research OREs wanted to engage caregivers in, including observational and intervention studies; and (3) questions regarding barriers and facilitators to caregiver engagement. NACC data were analyzed using descriptive statistics in SPSS v. 27. Open-ended responses were collected via SurveyMonkey then reviewed and summarized by the lead author.

Results

Table 1 shows the descriptive characteristics (M, SDs), chi-square tests and one-way ANOVAs on the main variables of interest. NACC co-participants (N=13,856) were primarily women, had a mean age of 71.94 years (13.87), and on average 15.27 years (2.86) of education. Latino co-participants were younger and had fewer years of education (M = 13.29, SD = 3.85). Co-participants knew participants about 42 years (14.82), with African Americans knowing participants the longest (M = 47.97) and Asian/Pacific Islanders the shortest (M = 39.40). Significant differences by race/ethnicity were found in gender: $\chi^2 = 97.25$, $p = .000$, relationship to participant: $\chi^2 = 1367.87$, $p = .000$, co-residence with the participant: $\chi^2 = 164.27$, $p = .000$, frequency of in-person visits: $\chi^2 = 93.55$, $p = .000$, and frequency of telephone contact: $\chi^2 = 113.81$, $p = .000$.

Survey responses were received from 11 out of 31 ADRC's, representing a 35% response rate. Results indicated that the majority of ADRCs engage caregivers at least somewhat in research (99%), agreed that ADRCs should engage caregivers in research (100%), and engaged caregivers at least quarterly (81%) in research (82%), education (91%), workshops/support groups (73%), and outreach (73%). Facilitators to caregiver engagement included expert or passionate staff, good community/investigator relationships; caregiver involvement through peer support and information exchange; and rewarding collaborations for ideas and recruitment. Conversely, barriers to caregiver engagement included limited caregiver time, communication, and follow-up; lack of standardized data collection; limited bandwidth of researchers; ADRC resources not applicable to caregivers; and cultural resistance to research.

Discussion

This study aimed to describe dementia caregiving in a database of ADRCs across the country. The majority of NACC co-participants were women, which is consistent with the caregiving literature across ethnic/racial groups.^{1, 4} However, among non-Hispanic White co-participants, the growing proportion of male caregivers reflects an emerging national trend.^{9, 4} Ethnic/racial co-participants were younger on average, which is consistent with

known literature.^{1, 4} However, co-participants were older than the national age of dementia caregivers and reports highlighting ethnic/racial caregivers.^{1, 4} While reasons for this are not well understood, one possible explanation is that individuals who seek care with ADRC affiliated memory clinics, or participate in studies, tend to be older.

Latino NACC co-participants were considerably younger than other groups, which is consistent with known literature, and may reflect multi-generational and working family caregivers.^{1, 4} Education was also significantly lower, underscoring the potential impact on health outcomes of health literacy and limited access to resources.³ African American co-participants had significantly longer relationships with participants. Reasons for this could reflect the common trend of adult children caring for a parent.^{1, 4} Conversely, Asian/Pacific Islander co-participants had significantly shorter relationships with participants which could reflect an increase of millennial caregivers.⁴

Most NACC co-participants lived with the participant, where the ongoing responsibility of care may create a challenge given participants' memory, behavioral, and functional changes.¹⁰ Literature supports higher prevalence of dementia-related behavior in communities of color, and shifting caregiving demands with disease progression and behavioral changes.² Significant ethnic/racial differences were present in the frequency of visits and telephone calls for co-participants who did not live with participants. While co-residence is a significant contributor to the stress of caregiving,^{2,4,5} co-participants who did not live with participants remained in daily contact in-person and/or on the phone. This finding presents a picture of need where telephone/in-person contact may reflect pending changes in living situation or the necessity of assistance with medical/nursing tasks, which is more prevalent in communities of color.^{1,5} Taken together, demographic characteristics of the sample represent variables which are associated with caregiver vulnerability to burden.^{1,4} Combined with the disproportionate incidence of Alzheimer's disease in communities of color¹⁰ co-participants are at further risk.

Given that the ORE is charged to provide bi-directional communication, survey respondents' current engagement of caregivers in research, frequency and multimodal engagement, and overwhelming agreement supporting caregiver involvement in research is unsurprising. Further, respondents' acknowledged facilitators that appear successful focus on communication, relationships, and the value caregivers feel from being included.

Nevertheless, barriers highlighted by survey respondents', while challenging, are not impossible to overcome and warrant discussion. Given limited caregiver time, online engagement, and varied communication techniques – including preferred language options – of both working and non-working caregivers may foster better communication and follow-up. Creating a standardized data repository, such as NACC, that includes caregiver specific questions with socio-cultural and environmental considerations could enhance ongoing engagement efforts or identify ideal times for tailored multicomponent interventions. For example, NACC could incorporate burden questions such as the Zarit Burden Inventory-4¹¹ screening, plus measures such as the Cultural Justification of Caregiving Scale.¹² When considering limited bandwidth of ADRC personnel and lack of applicable resources for caregivers, collaborating with other ADRCs and caregiver organizations to leverage

successful strategies, or the Alzheimer's Disease Outreach Recruitment and Engagement website can minimize these barriers. Finally, cultural research resistance is a real threat. However, acknowledging structural inequities and the lingering effects of historical abuse in vulnerable communities combined with building and maintaining trusting reciprocal relationships can be effective and beneficial.

We have identified some limitations. First, "co-participants" who completed baseline information, but may change over time may not reflect "caregivers". Second, the low survey response rate from ADRC OREs may not accurately reflect all ADRCs. One-time list-serv survey distribution without additional follow-up to increase completion response rates, and lack of personal outreach may reflect a missed opportunity for more robust response. Another limitation is the aggregation of racial/ethnic groups when understanding within group differences remains limited. Finally, using available variables as proxies to indicate the challenge of caregiving without specific caregiver burden measures to corroborate is also a limitation. Despite these limitations, using the NACC database provides uniform, national data across ethnic/racial groups. In addition, these data present a picture of ethnically/racially diverse co-participants and the potential challenges they experience, offering insight into a gap in caregiving research.

Current ADRC data being collected on caregivers are limited reinforcing caregiver "invisibility," and ethnic/racial inequities in dementia research, but promising opportunities exist to adjust practice. Reassess resources to meet socio-cultural caregiver needs, including materials that are appropriate for language, education level, and preferred format. In addition, accommodate clinic visits to reflect the diverse needs of adult child caregivers potentially balancing employment, school, or other caregiving demands and spouses lacking additional support in the home. Without question, incredible work is currently under way with unprecedented NIA funding, ADRC caregiver focused funding announcements, and federal legislation. There is opportunity for ADRCs to set a new standard and further engage diverse caregiver dyads in research. Leveraging collaborations with existing ADRCs, partnering with caregiver organizations, and creating a standardized caregiving repository for focused research on caregiver health outcomes are examples. In addition, increased and equitable funding from NIA to ORE cores would establish a new precedent to bolster effective participant programming as well as the recruitment and retention of diverse ORE leaders and personnel.

The effects of COVID-19 have been particularly harmful to caregivers due to isolation and dramatically reduced services. ADRC ORE cores are leading the way to pivot and support caregivers, especially those from historically excluded communities most at risk of COVID-19 and ongoing social and racial inequities, through expanded check-ins during the most challenging time in a century. Let us continue this work as we forge a path of expanded research and discovery. Together, let this be our Call to Action!

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Table 1

Demographics and Descriptives

	Non-Latino White n =11,158	African American n =1,455	Latino n =423	Asian Pacific Islander n =286	Total N=13,856	
Age (M, SD)	73.51 (13.34)	69.09 (13.67)	63.51 (14.59)	69.35 (14.41)	71.98 (13.87)	
Education (M, SD)	15.57 (2.65)	14.64 (2.69)	13.34 (3.81)	15.42 (2.91)	15.25 (2.87)	
Length Known (M, SD)	42.57 (14.62)	47.97 (15.01)	40.78 (15.25)	39.40 (16.24)	42.73 (14.81)	
	n (%)	n (%)	n (%)	n (%)	Total N=13,322	P
Female Gender	6857 (65.8%)	1080 (76.3%)	904 (73.8%)	209 (73.9%)	9140 (67.9%)	.000
Relationship to care recipient						
Spouse	7198 (69.1)	466 (32.9)	411 (33.6)	178 (62.9)	8301 (61.7)	
Adult Child	2341 (22.5)	689 (48.7)	613 (50.0)	76 (26.9)	3767 (28.0)	.000
Lives w/ care recipient	7640 (73.3)	852 (60.2)	763 (62.3)	208 (73.5)	9531 (70.8)	.000
Frequency in Person *						
Daily	17.7%	27.4%	32.3%	22.7%	21.1%	
At least weekly	59.0%	55.6%	54.5%	64.0%	57.9%	
At least monthly	16.3%	12.6%	10.4%	5.3%	14.8%	
<1x/month	7.0%	4.4%	2.8%	8.0%	6.2%	.000
Frequency telephone *						
Daily	39.6%	56.8%	56.3%	40.0%	44.1%	
At least weekly	41.8%	32.9%	32.9%	40.0%	39.3%	
At least monthly	4.4%	4.1%	3.9%	2.7%	4.3%	
<1x/month	14.2%	6.2%	6.9%	17.3%	12.2%	.000

* If caregiver does not live with care recipient how frequent are visits/telephone calls